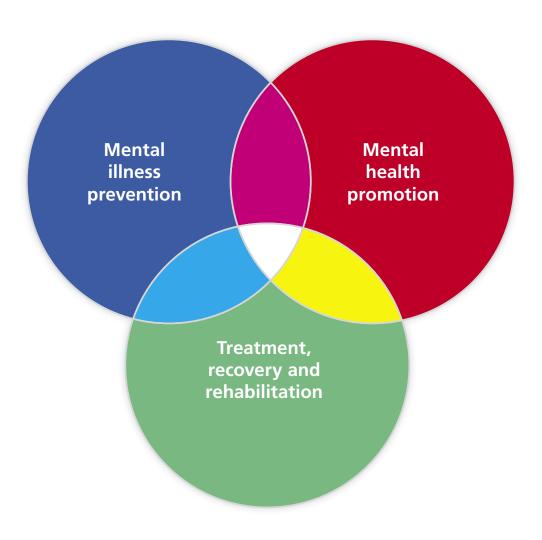
## Annual Report of the Chief Medical Officer 2013

Public Mental Health Priorities: **Investing in the Evidence** 





Doon Reader

Each year I publish two volumes of my annual report: a 'surveillance' volume which provides an epidemiological picture of aspects of the public's health, and an 'advocacy' volume which concentrates on a major public health area and examines it in detail, presenting recommendations for improvements to benefit the public's health.

For this advocacy volume, *Public Mental* Health Priorities: Investing in the Evidence, I have invited experts in many areas of mental health to author chapters covering this broad topic. This report includes a focus on the epidemiology of public mental health and the quality of the evidence base, 'horizon scanning' of innovation in science and technology, the economic case for good mental health and chapters outlining the importance of both treating mental health as equal to physical health and of focusing on the needs and safety of people with mental illness. The chapters also include authors' suggestions for improvement. From the stark information contained in the chapters of this report I developed my summary chapter. Here I make 14 recommendations to named organisations in order to effect positive change for the public's mental health, a topic that we simply cannot afford to ignore.

Prof Dame Sally C Davies

Sally C

# **Editors and authors**

#### **Editors and authors**

This report could not have been produced without the generous input of the following people.

#### **Editor-in-Chief**

Nisha Mehta<sup>1</sup>

1 Editor-in-Chief, Annual Report of the Chief Medical Officer 2013, Department of Health

#### **Project Manager and Sub-Editor**

Orla Murphy<sup>1</sup>

1 Chief Medical Officer's Events and Project Manager, Department of Health

#### **Policy Liaison**

Charlotte Lillford-Wildman<sup>1</sup>

1 Policy Manager, Department of Health

#### **Chapter Authors**

#### Chapter 1

Sally C Davies<sup>1</sup>

1 Chief Medical Officer and Chief Scientific Adviser, Department of Health

#### **Chapter 2**

Sally C Davies<sup>1</sup>, Nisha Mehta<sup>2</sup>

- 1 Chief Medical Officer and Chief Scientific Adviser, Department of Health
- 2 Editor-in-Chief, Annual Report of the Chief Medical Officer 2013, Department of Health

#### Chapter 3

Carmine M Pariante<sup>1</sup>, Akshay Nair <sup>2</sup>

- 1 Professor of Biological Psychiatry and Head of the Stress, Psychiatry and Immunology Laboratory and of the Section of Perinatal Psychiatry, Institute of Psychiatry
- 2 NIHR Academic Clinical Fellow, Department of Old Age Psychiatry, Institute of Psychiatry

#### **Chapter 4**

Chris Hollis<sup>1</sup>, Jennifer Martin<sup>2</sup>, Sarah Amani<sup>3</sup>, Rebecca Cotton<sup>4</sup>, Mike Denis<sup>5</sup>, Shon Lewis<sup>6</sup>

- 1 Clinical Director, NIHR MindTech Healthcare Technology Co-operative, Institute of Mental Health, University of Nottingham
- 2 Programme Manager, NIHR MindTech Healthcare Technology Cooperative, Institute of Mental Health, University of Nottingham
- 3 Chief Clinical Information Officer, Surrey and Borders Partnership NHS Foundation Trust
- 4 Director of Policy, Mental Health Network, NHS Confederation
- 5 Director of Information Strategy, Oxford Academic Health Science Network
- 6 Director, Institute of Brain, Behaviour and Mental Health, University of Manchester, Manchester Academic Health Science Centre, Manchester Mental Health and Social Care Trust

#### Chapter 5

Peter Fonagy<sup>1,2</sup>

- 1 Head of Research Department of Clinical, Educational and Health Psychology and Freud Memorial Professor of Psychoanalysis, University College London
- 2 Chief Executive, The Anna Freud Centre, London

#### **Chapter 6**

Tamsin Ford<sup>1,2,3</sup>, Oana Mitrofan<sup>4</sup>, Miranda Wolpert<sup>5,6</sup>

- 1 Professor of Child and Adolescent Psychiatry, Institute of Health Research, University of Exeter Medical School
- 2 Unpaid Director, Child Outcomes Research Consortium
- 3 Honorary Consultant, Devon Partnership Trust
- 4 Academic Clinical Lecturer, Institute of Health Research, University of Exeter Medical School
- 5 Director, Evidence Based Practice Unit, University College London and Anna Freud Centre
- 6 Director, Child Outcomes Research Consortium

#### **Chapter 7**

Stephen Stansfeld<sup>1,2</sup>, Sally McManus<sup>3</sup>, Kamaldeep Bhui<sup>4</sup>, Peter Jones<sup>5,6</sup>

- 1 Professor of Psychiatry, Centre for Psychiatry, Barts and the London School of Medicine and Dentistry, Queen Mary University of London
- 2 Honorary Consultant Psychiatrist, East London NHS Foundation Trust
- 3 Research Director, NatCen Social Research
- 4 Professor of Cultural Psychiatry and Epidemiology, Wolfson Institute of Preventive Medicine, Queen Mary University of London, East London NHS Foundation Trust
- 5 Professor of Psychiatry, University of Cambridge
- 6 Director, National Institute for Health Research, Collaboration for Leadership in Applied Health Research and Care, East of England

#### **Chapter 8**

Robert Stewart<sup>1,2</sup>

- 1 Professor of Psychiatric Epidemiology and Clinical Informatics, King's College London
- 2 Consultant Psychiatrist, South London and Maudsley NHS Foundation Trust

#### **Chapter 9**

Martin Knapp<sup>1</sup>, Valentina lemmi<sup>2</sup>

- 1 Professor of Social Policy and Director, Personal Social Services Research Unit, London School of Economics and Political Science
- 2 Research Officer, Personal Social Services Research Unit, London School of Economics and Political Science

#### **Chapter 10**

Max Henderson<sup>1</sup>, Ira Madan<sup>2</sup>

- 1 Senior Lecturer in Epidemiological and Occupational Psychiatry, Institute of Psychiatry, King's College London
- 2 Reader in Occupational Medicine, King's College London

#### Chapter 10 (special case study)

Clare Gerada<sup>1</sup>

1 Medical Director, Practitioner Health Programme, London

#### **Chapter 11**

Graham Thornicroft<sup>1</sup>, Sara Evans-Lacko<sup>2</sup>, Claire Henderson<sup>3</sup>

- 1 Professor of Community Psychiatry, King's College London, Institute of Psychiatry
- 2 Lecturer, King's College London, Institute of Psychiatry
- 3 Clinical Senior Lecturer, King's College London, Institute of Psychiatry

#### Chapter 12

Graham Thornicroft<sup>1</sup>, Mary Docherty<sup>2</sup>

- 1 Professor of Community Psychiatry, Institute of Psychiatry, King's College London
- 2 NIHR Academic Clinical Fellow, Institute of Psychiatry, King's College London

#### Chapter 13

Matthew Hotopf<sup>1,2</sup>, Lance McCracken<sup>3</sup>

- 1 Professor of General Hospital Psychiatry, King's College London, Institute of Psychiatry
- 2 Director NIHR Mental Health Biomedical Research Centre, South London and Maudsley NHS Foundation Trust
- 3 Professor of Behavioural Medicine, King's College London, Institute of Psychiatry

#### **Chapter 14**

Louise M Howard<sup>1,2</sup>, Jennifer Shaw<sup>3,4</sup>, Sian Oram<sup>5</sup>, Hind Khalifeh<sup>6,7</sup>,Sandra Flynn<sup>8</sup>

- 1 Professor in Women's Mental Health and NIHR Research Professor, Institute of Psychiatry, King's College London
- 2 Consultant Perinatal Psychiatrist, South London and Maudsley NHS Foundation Trust
- 3 Professor of Forensic Psychiatry and Consultant Forensic Psychiatrist, University of Manchester
- 4 Consultant Forensic Psychiatrist, Lancashire Care NHS Foundation Trust
- 5 Lecturer, Institute of Psychiatry, King's College London
- 6 Academic Psychiatrist, King's College London
- 7 Consultant Psychiatrist, South London and Maudsley NHS Foundation Trust
- 8 Research Fellow, Centre for Mental Health and Risk, University of Manchester

#### **Chapter 15**

Keith Hawton<sup>1</sup>, David Gunnell<sup>2</sup>, Navneet Kapur<sup>3</sup>

- 1 Professor of Psychiatry and Director of the Centre for Suicide Research, Department of Psychiatry, University of Oxford
- 2 Professor of Epidemiology, School of Social and Community Medicine, University of Bristol
- 3 Professor of Psychiatry and Population Health and Head of Research, Centre for Suicide Prevention, Centre for Mental Health and Risk, University of Manchester

#### **Chapter 16**

John Strang<sup>1,2</sup>, Colin Drummond<sup>3,4</sup>, Ann McNeill<sup>5,6</sup>, Malcolm Lader<sup>7</sup>. John Marsden<sup>8,9</sup>

- 1 Professor of Addictions and Director, National Addiction Centre, Institute of Psychiatry, King's College London
- 2 Leader of Addictions CAG (Clinical Academic Group), Kings Health Partners Academic Health Sciences Group, London
- 3 Professor of Addiction Psychiatry, National Addiction Centre, Institute of Psychiatry, King's College London
- 4 Clinical Director for Alcohol, South London Health Innovation Network
- 5 Professor of Tobacco Addiction, National Addiction Centre, Institute of Psychiatry, King's College London
- 6 Deputy Director, UK Centre for Tobacco and Alcohol Studies, Nottingham
- 7 Emeritus Professor of Clinical Psychopharmacology, National Addiction Centre, Institute of Psychiatry, King's College London
- 8 Professor of Addiction Psychology, National Addiction Centre, Institute of Psychiatry, King's College London
- 9 Senior Academic Advisor for the Alcohol, Drug and Tobacco Division, Health and Wellbeing Directorate, Public Health England

#### **Editors and authors**

#### **Chapter 17**

Kamaldeep Bhui<sup>1</sup>, Jean O'Hara<sup>2</sup>

- 1 Professor of Cultural Psychiatry and Epidemiology, Wolfson Institute of Preventive Medicine, Queen Mary University of London, East London NHS Foundation Trust
- 2 Consultant Psychiatrist and Clinical Director, Behavioural and Developmental Psychiatry Clinical Academic Group, King's Health Partners Academic Health Sciences Centre, South London and Maudsley NHS Foundation Trust

#### **Appendix 1**

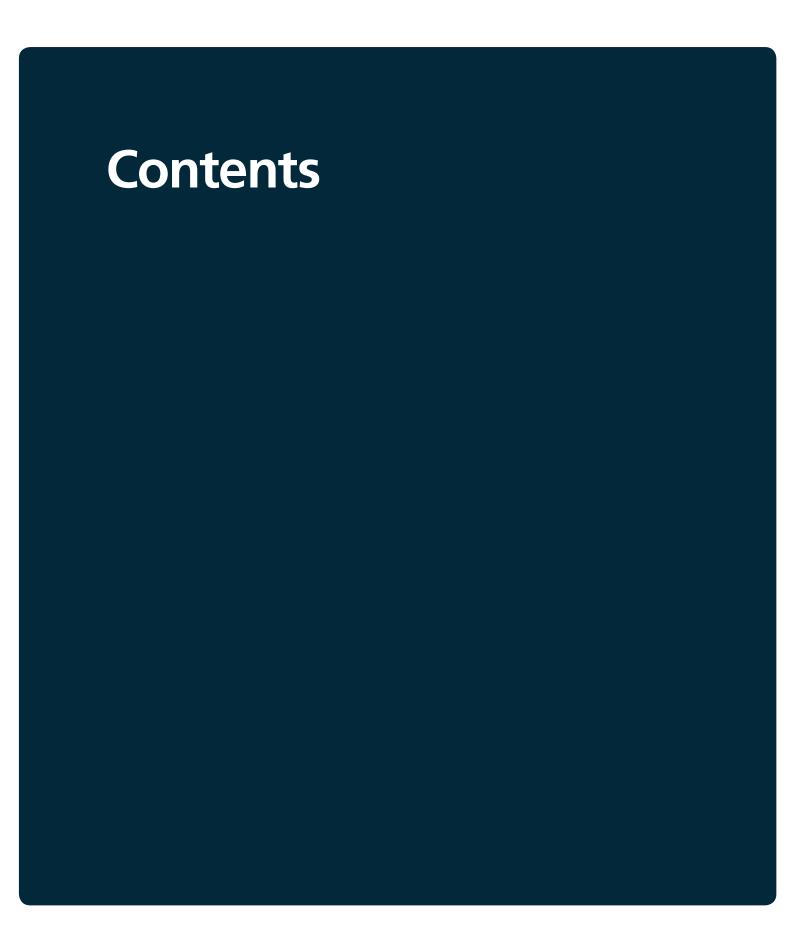
Ann Bowling<sup>1</sup>

1 Professor of Health Sciences, University of Southampton

#### **Appendix 2**

Alison Tingle<sup>1</sup>

1 Research Analyst, Department of Health

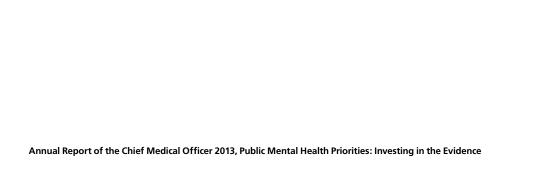


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Section 1

# **Chief Medical Officer's Introduction**



#### Chapter 1

# **Chief Medical Officer's summary**

### **Chapter author** Sally C Davies<sup>1</sup>

1 Chief Medical Officer and Chief Scientific Adviser, Department of Health

#### Introduction

My annual report aims to fulfil two functions: to increase transparency about progress within public health and to help drive forward improvements across England. To achieve this, as with my 2011 and 2012 report, I am continuing with two volumes. The first volume is a compendium of data and information used to describe the health of the population. The narrative of this, the second volume (hereafter called 'this report'), fulfils the independent advocacy role of the Chief Medical Officer.

#### The purpose of this report

I have chosen to focus on population mental health for a number of reasons:

- Mental illness is the largest single cause of disability and represents 28% of the national disease burden in the UK. It is the leading cause of sickness absence in the UK, accounting for 70 million sick days in 2007.
- Mental illness costs the UK economy £70-£100 billion per year; 4.5% of Gross Domestic Product.
- There is a very significant overall treatment gap in mental healthcare in England, with about 75% of people with mental illness receiving no treatment at all.
- There is an unacceptably large 'premature mortality gap': people with mental illness die on average 15–20 years earlier than those without, often from avoidable causes.
- Whilst there is a wealth of robust evidence for public health approaches to mental illness prevention and mental health promotion, England needs a better defined, policy-relevant focus on these concepts.
- Despite a welcome policy focus on mental illness, there has been a real-terms fall in investment of resources in mental health services in England since 2011.

#### Box 1.1 Public mental health and mental illness – definitions

Public mental health – the mental health variations of importance exhibited by populations. Consists of 'mental health promotion', 'mental illness prevention' and 'treatment and rehabilitation'.

Mental illness – description of the experience, defining attributes or diagnosis of those who meet ICD-10 or DSM-5 criteria for mental disorders. This includes common mental disorder (including anxiety and depression), which affects nearly 1 in 4 of the population, and severe mental illness, such as psychosis, which is less common, affecting 0.5–1% of the population.\*

#### The scope of this report

In this report I focus on public mental health and the burden of mental illness in England. I include specific sections on areas of particular importance. These include:

- Science and technology
- Mental health across the life course
- The economic case for better public mental health
- Parity of esteem
- Needs and safety

I have built upon chapters in my 2012 annual report, *Our Children Deserve Better: Prevention Pays*, by further developing the case for prevention of mental illness and promotion of mental health in children and young people. I welcome the terms of the Health Select Committee Inquiry into Child and Adolescent Mental Health Services (CAMHS), and I have included a chapter in this report which gets into the detail of these important issues.

I have chosen not to specifically focus on dementia in this report because it is such a large and important topic that it would have been impossible to do it justice within this volume. I have included consideration of both dementia and physical comorbidities in a Life Course chapter which focuses on the mental health of older adults. I have not specifically considered intellectual disability but I have included a detailed case study about the mental health and special needs of people with intellectual disability in Chapter 17, 'Ethnic inequalities, complexity and social exclusion in mental health'. This chapter considers ways in which mental health more broadly can learn from a model of best practice service delivery aimed at meeting the needs of these vulnerable and complex patients.

<sup>\*</sup> According to the 2007 Adult Psychiatric Morbidity Survey

## The intended audience for this report

This first chapter is my response to the evidence base underpinning the challenges facing public mental health in England today, and is therefore aimed at the public health profession and policy makers. The report shines a light on those issues that require particular policy focus and makes recommendations for specific bodies including:

- policy makers
- professionals involved in the collection and management of data
- research and methodology institutions
- public health practitioners
- professional organisations including the medical royal colleges
- clinical guideline groups
- health and social care commissioners
- providers of all health services
- medical trainers.

The remainder of this report consists of chapters written by internationally recognised experts who were asked to provide me with the best evidence about key issues in public mental health in England today. I have also considered several recent, high profile reports which have contributed to this dynamic field. The report chapters were written to inform me, as Chief Medical Officer, of the areas I need to champion for action. The chapters were written by the authors and represent their views rather than mine. But they provide the evidence base on which my calls for action are made.

The report is not aimed at the general public but, as it addresses issues that affect all of us, so it will be useful to those with an interest in the area.

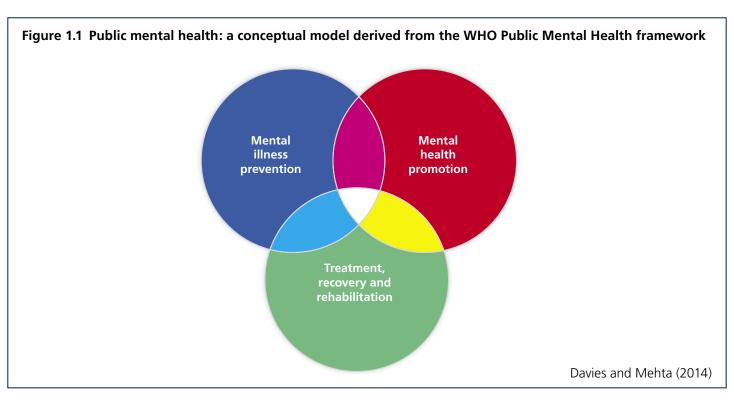
#### Report summary

This report is intended to be an evidence-based point of reference which brings together public mental health evidence and policy in England. I recommend the wealth of knowledge and expertise contained in the individual chapters, and in this summary I will bring out the key messages from each of the report sections which follow.

#### **Chief Medical Officer's Introduction**

In a departure from the format of previous reports, Chapter 2 'Public mental health: evidence based priorities' forms part of the Chief Medical Officer's Introduction to the report but is additional to the Chief Medical Officer's summary. I have co-authored it with the report's Editor-in-Chief, to give consideration to the evidence base in public mental health, which is a vast and complex field, and in which I have heard repeated calls for clarity and quality of evidence.

Chapter 2 sets out the evidence that frames our understanding of public mental health, and I conclude that our approach to this subject should no longer be framed in terms of 'well-being'. I do not refer here to the concept of 'well-being' more generally as it applies more broadly across the business of Government or indeed to 'health' more generally. I welcome the consideration of the wider determinants of health in policy making. I reiterate that I refer here to the concept of well-being as relates only to mental health.



After reviewing the evidence I conclude that well-being does not have a sufficiently robust evidence base commensurate with the level of attention and funding it currently receives in public mental health at national and local government level. Well-being, as a field within mental health, has not evidenced an acceptable definition or set of metrics. It is unclear how concepts and measures that do exist relate to populations with mental illness. Contrary to popular belief, there is no good evidence I can find that well-being interventions are effective in primary prevention of mental illness, or can 'shift the normal distribution curve' described by Rose and hypothesised by the Foresight report in 2008. The result is that the public health needs of approximately 1 in 4 of the population who have a mental illness, 75% of whom receive no treatment, risk being side-lined in the enthusiastic pursuit of a policy agenda that is running ahead of the evidence.

In pointing out the lack of evidence for well-being, I have been asked to 'take a leap of faith' about well-being in mental health. As Chief Medical Officer I will not take a leap of faith with people's health. The truth is that well-being in mental health is one poorly evidenced strand of a much bigger picture, and I recommend that bigger picture to policy makers. If we take the lead from the WHO and frame the subject as 'mental health promotion', 'mental illness prevention' and 'treatment and rehabilitation' (see Figure 1.1), then it becomes immediately apparent that we already have a good deal of evidence supporting a public health approach to mental health, and that effective and costeffective interventions should be the priority. Much of the evidence is contained within the chapters of this report. This is 'low-hanging fruit'; we must not ignore it, or focus instead on 'well-being'; we must not re-badge it as 'well-being evidence'; and we must not reinvent the wheel.

#### Science and technology

- Chapter 3, Neuroscience and common mental disorder
- Chapter 4, Technology and mental health
- Chapter 5, Developmental psychopathology a perspective

The inclusion of this section brings attention to the quality and breadth of scientific work currently underway to promote mental health, prevent mental illness and develop more effective treatments for those with and recovering from mental illness. The chapters cover advances in fields as diverse as neuroimaging, neuropsychology, genetics, blood based biomarkers and animal and cellular models of disease. Some of the work is already available clinically, others could have widespread clinical utility within the next 10 years, especially in the emerging area of 'personalised medicine'. Technology offers the potential to transform mental healthcare delivery, to enhance adherence support and symptom monitoring and facilitate more timely early interventions in pathways to illness. Together, the chapters demonstrate that the 'biomedical', 'psychological' and 'social' models of mental illness are not antithetical, but are in fact increasingly conceptualised within a single unifying framework. Chapter 5, 'Developmental psychopathology – a perspective',

supplements this by exploring the evidence that increasingly makes the case that developmental psychopathology is not limited to risk and protective factors, but is concerned with identifying mediating mechanisms. The chapter reviews the interplay between social, psychological and biological attributes of normal development across the lifespan and identify precursors and pathways leading to disorder.

#### Life course

- Chapter 6, Life course: children and young people's mental health
- Chapter 7, Life course: adults' mental health
- Chapter 8, Life course: older adults' mental health

This section builds on bio-psycho-social explanations of precursors and pathways leading to disorder in the Science and Technology Section. The content of Chapter 6, 'Life course: children and young people', was included in response to my concerns about children's mental health and their access to services which were raised in the mental health chapter of my 2012 annual report 'Our Children Deserve Better: Prevention Pays'. Building on previous work, this chapter considers that childhood behavioural problems, bullying and self-harm stand out as particular issues that warrant improved interventions and that children, young people and their families should be actively involved in service development and improvement.

I welcome areas of positive development: greater collaboration and consistency across CAMHS are coalescing around shared standards of practice that combine implementation of evidence-based practice with a commitment to develop the practice-based evidence base, service user involvement and collaborative working. One of the recommendations in my 2012 annual report was to repeat the British Child and Adolescent Mental Health Survey (B-CAMHS). I am pleased that the Department of Health has agreed funding, and is in the process of commissioning a new national survey of children and young people's mental health. I also welcome the recently announced Children and Young People's Mental Health and Well-Being Taskforce, which will focus on innovative solutions to improve outcomes for children and young people's mental health. NHS England's CAMHS Tier 4 Report, published in July 2014, identifies specific improvements that are required as an immediate and urgent priority through national commissioning, and will be a useful resource in this area going forward. Just as the seeds of a long and healthy life are sown in childhood so, too, are the origins of much mental illness. Chapter 7, 'Life course: adult mental health', uses rich data from the Department of Health Adult Psychiatric Morbidity Surveys to demonstrate that efforts to understand and alleviate mental disorders of adulthood must take into account a life course perspective. Key content of this chapter covers the epidemiology of adult population mental health, with particular reference to gender, ethnicity, economic context, debt, housing conditions, social relationships, caring responsibilities, working conditions/ unemployment and interpersonal violence. Chapter 8, 'Life course: older adult mental health', covers older adults with a

mental illness other than dementia. These people have been substantially underrepresented in policy, falling between the focus on 'mental health in working age adults' and 'dementia'. The evidence is compelling for action on the very treatable but often neglected problems of depression, substance misuse, psychosis, and related issues of social isolation, physical comorbidities, delirium and frailty as well as dementia.

#### The economic case for better mental health

- Chapter 9, The economic case for better mental health
- Chapter 10, Mental health and work

Chapter 9 draws upon themes contained within the rest of the report to make a compelling economic case for good mental health which has the potential to realise substantial savings across the entire economy. For example, service costs associated with childhood psychiatric disorders were twelve times greater for frontline education services than for specialty mental health service. The cost of a completed suicide for someone of working age in the UK exceeds £1.6 million. The chapter identifies evidence and an economic framework to guide commissioners to make cost effective investment decisions. Chapter 10 focuses specifically on the compelling evidence for the health and economic benefits that will accrue from better mental health in the working age population. At between £70 billion and £100 billion per year, the cost of mental illness to the UK economy is significant. The economic impact arises from sickness absence, benefit provision and loss of productivity. Less quantifiable but also important are the costs generated from caring by partners and family members. Since 2009 the number of sick days lost to 'stress, depression and anxiety' has increased by 24%; the number lost to 'serious mental illness' has doubled. In 2013, 40.9% of ESA (Employment and Support Allowance) recipients had 'mental and behavioural disorders' as their primary condition. This may be an underestimate from routinely collected data. On the other hand, 60-70% of people with common mental disorders are in work. Strategies in the workplace to prevent mental ill health have not proved cost effective, and focusing on harmful 'stresses' in the workplace risks modifying expectations in a way that perversely leads to an increase in illness reporting; better to promote ways in which well-designed work can lead to psychological benefits. Measures that increase control, such as increased employee flexibility improve mental health. Early and regular contact from managers during sick leave is associated with a more rapid return to work. Workers with mental illness do not need to be fully recovered to return to work. The longer an individual is away from work, the more difficult it is to return. Temporary adjustments, such as parttime working and altered work hours facilitate return to work and may play an important role in recovery. Questioning the likelihood of workplace well-being interventions having any effect on those whose resources are already low due to mental illness, this section recommends that all employers should instead ensure that they are complying with current health and safety legislation and NICE public health guidance.

#### Parity of esteem

- Chapter 11, Stigma and discrimination
- Chapter 12, Mind the gaps: treatment, funding, access and service provision
- Chapter 13, Physical health and mental illness

This section makes the evidence-based and ethical case for parity of esteem: treating mental and physical health outcomes as equally important. It builds on the excellent work in the 2013 Royal College of Psychiatrists report *Wholeperson care: from rhetoric to reality.* This was followed up by the 2014 BMA Board of Science report *Recognising the importance of physical health in mental health and intellectual disability* which makes an insightful and evidence-based case for integration between physical and mental healthcare.

At the root of many of these serious public health challenges lies stigma and discrimination, with their severe and chronic impact on the lives of people with mental illness, which are driving factors in maintaining the status quo of poor access to healthcare, reduced life expectancy, exclusion from education and employment, victimisation, poverty and homelessness. The chapter reviews evidence for effectiveness of antistigma interventions and concludes that carefully delivered interventions (such as the modest gains made by England's 'Time to Change' programme), both local and national do reduce stigma and discrimination, if sustained over a sufficiently long term. Evidence is strongest for interventions using social contact.

The gaps in treatment, funding, access and service provision described in Chapter 12, 'Mind the gaps: treatment, funding, access and service provision', are partly related to historical structural discrimination against people with mental illness. The evidence in this chapter has been pieced together using many different sources to try and bring clarity to the 'gaps' issue, which has, over this parliament, finally become the focus of much needed media and policy attention. Funding, access and treatment outcomes should follow, and this chapter provides the evidence for a way forward. It seems clear that we have recently seen a fall in investment and expenditure, despite evidence of an increase in the mental illness burden. Data in this area are weak and must be improved, but the figures we do have are stark: in addition to the 75% treatment gap, the chapter provides evidence of real-terms reductions in investment in mental health in England. There appear to be considerable discrepancies between overall national figures for resource reductions and some figures available locally. In the period 2005/06 – 2012/13, estimates of the number of adults with mental health problems receiving state-funded social care services showed a 48% reduction in England – the largest fall in services provided for any group assessed. In relation to the actual disease burden attributable to mental illness, mental health care accounts for 13% of spending, whilst mental illness is responsible for 28% of all morbidity in England.

On a more positive note, I welcome the increase in funding for the world-leading, cost-effective 'Improving Access to Psychological Therapies' (IAPT) programme. However IAPT does not yet meet the needs of the population it serves and it should be supported to continue its work to deliver NICE recommended standards of care to all who need them. IAPT might in future usefully be integrated into existing services where relevant, particularly for those with longterm physical health conditions (LTCs). Chapter 13, 'Physical health and mental illness', picks up on this by making the case for better mental health care for those with LTCs. The journey a patient with an LTC takes is often one of loss, threat and uncertainty, which are established risk factors for anxiety and depression. In England, when people with clinical disease are sampled and studied, the prevalence of common mental disorder (CMD) is high. For example nearly 50% of women with breast cancer recruited from a London hospital had depression, anxiety or both in the year after diagnosis. In a Manchester study of myocardial infarction, 20% of those affected had depression with a further 21% of those followed over a year developing depression in that time. Similar rates of CMD are found in populations with diabetes, foot ulcers, COPD (chronic obstructive pulmonary disease), chronic pain, rheumatoid arthritis, complex orthopaedic injuries and hepatitis C. The key message is that CMDs are highly prevalent with LTCs. Yet there is substantial evidence that the conventional treatments for anxiety and depression work irrespective of the presence of physical comorbid disease. NICE recommends screening for depression in patients with LTCs but for this to be effective it must be done in tandem with the development of care pathways that offer a different approach to management once depression is detected. This has the potential to make a profound impact on all patient outcomes: a population approach to identification and management of depression in patients with heart disease or diabetes has been shown to improve depression outcomes but also improves diabetic control, blood pressure and cholesterol levels.

#### **Needs and safety**

- Chapter 14, Violence and mental health
- Chapter 15, Suicide and self-harm
- Chapter 16, Addictions, dependence and substance abuse
- Chapter 17, Ethnic inequalities, complexity and social exclusion in mental health

This section reflects the need to focus on important topics within public mental health which do not obviously fall within the remit of the rest of the report, but which are drawn from areas of concern which must be considered to ensure the needs of the population are met safely and fairly. Chapter 14, 'Violence and mental health' lays out the evidence relating to the complex, interrelated problems of violence and mental health in terms of violence as a risk factor for the development of mental illness, and mental illness as a risk factor for being both a victim of and a perpetrator of violence.

It is estimated that a quarter to a third of the burden of adult psychiatric disorders is attributable to the effect of childhood abuse. Being a victim of sexual or domestic violence in adulthood is associated with the onset and persistence of depression, anxiety and eating disorders, substance misuse, psychotic disorders and suicide attempts. People with pre-existing mental illness are up to ten times more likely to be the victims of violence than the general population. In relation to the risk of perpetration of violence by people with mental illness, it is clear that most people with mental illness are not violent and most people who are violent are not mentally ill. There is a widely held belief that people with mental illness are violent and unpredictable, yet the estimated attributable risk of violence by people with mental illness ranges between 3% and 5%.

Chapter 15, 'Suicide and self-harm', provides an overview of the epidemiology of suicide and self-harm in England. I note that suicide rates have increased by 4% since 2006/07 when they were at their lowest recorded rate, most likely due to the impact of the recent economic recession. Suicide is three times higher in males than females and a total of 4,513 suicides were recorded in England in 2012. The main method of suicide is hanging, and the use of this method is increasing. I am also concerned about the recent rise in the new method of helium suicides in the UK.

The rate of self-harm in the English population equates to 245,000 hospital presentations per year. I note with concern that 6–10% of adolescents in the community report having self-harmed in the previous year, yet only about one in eight of this group report having presented to clinical services. I welcome the work of England's National Suicide Prevention Strategy as well as the development of public health and local authority policies. Research has shown that services that implemented the National Confidential Inquiry recommendations to improve the safety of specialist mental health services had a lower suicide rate than those that did not. These changes may have prevented 200 to 300 deaths per year. I am encouraged that services for self-harm are improving. Nine out of ten hospitals have specialist teams for the assessment and management of self-harm, combined with evidence to suggest that brief psychological treatment may reduce repetition. However only 57% of hospitals in a representative England sample were meeting the provisions set out by NICE that all self-harm patients should receive a psychosocial assessment of needs and risk in hospital.

Chapter 16, 'Addictions, dependence and substance abuse' addresses addiction/dependence on substances with dependence potential and abuse liability where key, evidence based actions can be identified. This is important as the chapter identifies that there are preventive and secondary treatments which continue to be commissioned and provided in England despite the absence of an evidence base, or indeed where studies have demonstrated a lack of effectiveness. Major public health challenges related to alcohol, tobacco, benzodiazepine and heroin misuse are discussed in turn, alongside the best evidence for the scale of the problem, resulting health problems and responses,

the importance of addressing addictions, and the resulting key messages for policy and commissioning. In particular, I caution against any dismantling of specialist centres since this reduces capability to treat the most 'hard-to-treat' patients whilst also impairing training and research capacity.

Chapter 17, 'Ethnic inequalities, complexity and social exclusion in mental health', pulls many of the themes featured elsewhere in the report together. It takes a thoughtful approach to inequalities in experience and outcome for particularly vulnerable patient groups. Drawing on the evidence base, the chapter makes suggestions for improving cultural competency in the workforce and improving awareness of cultural factors in commissioning. The chapter also discusses the specific issues surrounding emergency care pathways for patients with mental disorder and their frequency of contact with the police in the black Caribbean community. Drawing this content together, the chapter makes a compelling case for considering inequalities and social exclusion specifically within public mental health. It echoes other chapters throughout the report in calling for moving this towards an integrated strategy that places mental health within a public health framework using a bio-psychosocial approach.

#### Recommendations

In this section I lay out my recommendations. I have formulated these recommendations by studying the number of common themes brought to my attention by the broad range of stakeholders who generously contributed to the content and production of this report. I have considered the evidence, consulted widely and group my recommendations under the following headings:

- Commissioning and service development
- Information, intelligence and data
- Work
- Workforce training and practice
- Policy

#### Commissioning and service development

Public mental health is most usefully framed according to the WHO model of 'mental health promotion', 'mental illness prevention' and 'treatment, recovery and rehabilitation'. There is a strong evidence base for effective interventions in these interrelated spheres which is drawn from several different academic fields which are discussed at length in Chapter 2. There is insufficient evidence for well-being interventions for adult mental health to be prioritised at this time. My first recommendation is therefore:

#### **Recommendation 1**

Commissioners in Local Authorities, Health and Wellbeing Boards and Clinical Commissioning Groups should follow the WHO model in commissioning and prioritising evidence based interventions for mental health promotion, mental illness prevention and treatment and rehabilitation. Well-being interventions should not be commissioned in mental health as there is insufficient evidence to support this.

Safe, integrated mental and physical healthcare should be a shared goal across sectors and is crucial to achieve parity of esteem and outcomes in mental and physical health. This includes the mental health of people with physical illness and the physical health of people with mental illness. All Commissioners and Health and Well-being Boards should be informed by a Joint Strategic Needs Assessment (JSNA) which contains the information needed to plan services to meet the integrated mental, physical and social care needs of their populations. This data is now provided for ease of access by the Mental Health Intelligence Network and includes the information for all 16 mental health conditions categories on local needs, high risk groups who should be prioritised for prevention, the baseline levels of access to evidence based effective care, waiting times that impact on outcomes, standards, quality and investment. I therefore recommend:

#### **Recommendation 2**

All Health and Wellbeing Boards should be informed by a Joint Strategic Needs Assessment (JSNA) which includes the information needed to plan services to integrate the mental and physical health needs of their populations. The required information is provided for ease of access by the Mental Health Intelligence Network.

#### **Recommendation 3**

The Outcomes Frameworks should work together to develop a metric that recognises patient experience of the integration of their care and leads to rewards for effective integration around the patient's health and social care needs.

I welcome the success of the innovative Birmingham RAID (Rapid Assessment, Interface and Discharge) service for hospital liaison psychiatry. I note that it is effective and costeffective in evaluations, and that the economic benefits associated with the service for all adults predominantly lay in reduced length of hospitalisation for older adults. Building on the latter finding, the needs of older patients should be a key consideration in the commissioning of liaison service provision. Mental health problems in older adults are common, often undiagnosed but as amenable to established treatments as in other groups. Helping people with combined physical, psychological and social difficulties in the context of ageing and end of life requires specialism. This could be compromised by any move to generic 'age-less' services.

Building on the success of hospital liaison models such as RAID, I suggest that community services should be enhanced in a similar way so that community staff can refer patients with complex physical and mental health presentations for specialist advice. I welcome the progress made by the Torbay and South Devon Integrated Care Pioneer in primary care psychiatry which provides primary care teams with outreach mental health practitioners to support clinicians manage people with complex psychiatric morbidities. I therefore recommend:

#### **Recommendation 4**

The Torbay and South Devon Integrated Care Pioneer service in primary care psychiatry should be evaluated with a view to further development and piloting elsewhere in England.

#### Information, intelligence and data

Good health support and services should be based on high quality, accurate data. I welcome the development of the Mental Health, Dementia and Neurology Intelligence Network (MHIN), which will bring together the range of publicly available data presented by CCGs and Local Authority areas. This is an important step forward in parity and public transparency of data for public mental health. As England considers its approach to the collection of health data more broadly, I am mindful of the fact that any mental health data

collection system based on an 'opt-in' premise would de facto discriminate against people with mental illness. I note that there is a need for better awareness and analysis of the links between employment status and mental health, and for that we need better data.

Finally, I applaud the collegiate and scientific approach taken towards progressing the complex agenda of measuring national well-being taken by the Office for National Statistics (ONS).

#### **Recommendation 5**

I recommend that arrangements put in place for mental health data collection are not different to those put in place for physical health, in keeping with the stated policy of parity.

#### **Recommendation 6**

Employment is central to mental health and it needs to be a routine part of patient records. So, the Health and Social Care Information Centre, working with the Royal College of General Practitioners and other Royal Colleges, should review the existing taxonomy for the routine collection of employment data to ensure that it is usable and can be coded across all care settings. Employment status should then become a routine part of all patient records.

#### **Recommendation 7**

I recommend that the ONS continue to work with expert psychometricians as they further develop the Measuring National Wellbeing Programme and all other related activity.

#### **Recommendation 8**

The Mental Health Intelligence Network should link routine mental health data to longitudinal mental health survey data to better understand patterns of mental illness across the community, including those affected by the 75% treatment gap.

#### Work

I note with concern that in England 113 million working days are lost to sick leave each year. Ill health in the working age population (aged 16–64 years) costs the economy £13 billion in health-related sickness benefits and £9 billion to employers in terms of sick pay and associated costs. Those off work for more than 6 months have only a 20% chance of returning to work in the next 5 years. I am also concerned that mental illness is both a risk factor for 'worklessness', and an outcome of it. Individuals can get trapped in a cycle where their mental illness creates and maintains their 'worklessness', which in turn worsens their mental health. On the other hand 60–70% of people with common mental disorders (such as depression and anxiety) are in work and there is a strong economic imperative to keep them in work and address their

mental health. I welcome the Department for Work and Pensions' 'Health and Work Service' but note that it does not include any specific psychiatric input for people who have been out of work for 4 weeks and who may have a mental illness. I therefore recommend:

#### **Recommendation 9**

NICE should analyse the cost benefit of providing a fast and efficient integrated pathway for psychiatric provision for people with mental illness, who risk falling out of work, aimed at maximising their ability to stay in work.

#### Workforce training and practice

As part of a drive to achieve parity of esteem for mental health, it is important that medical training and practice recognises the mental health needs of patients. This will require changes to the content and structure of training programmes. I welcome the published target of 50% of all Foundation Year doctors having completed a post in psychiatry by 2016, and, as I have said previously I support the extension of GP training by 1 year.

#### **Recommendation 10**

I recommend that there should be a period of specific mental health training in GP training. A core part of the training should include specific training for awareness about the consequences of violence on mental health across the life course.

#### **Recommendation 11**

I recommend that Health Education England should publish a report in 2015 on progress against its target of 45% of Foundation Year doctors undertaking a post in psychiatry from 2014–15 onwards.

#### **Recommendation 12**

If GPs suggest using new technologies to improve mental health to patients they should draw these from an approved list of NHS evaluated technologies which have met the standards required by evidence based medicine.

#### Policy

Stigma and discrimination are major barriers to full participation in healthcare, education and citizenship in England. They reduce the opportunities for people with mental illness to gain employment, to receive the quantity and quality of mental and physical health care needed, and to form important social relationships. Since 2007 significant, but modest, gains have been made in the reduction of stigma and discrimination during the period of the 'Time to Change' programme. Most people with mental illness however, still experience these negative reactions, and many then

internalise these forms of rejection in ways that diminish their life opportunities. The evidence clearly shows that carefully delivered interventions, both local and national, do reduce stigma and discrimination, if sustained over a sufficiently long term. The interventions with strongest evidence are those using social contact. I look forward to seeing the development of evidence based social contact programmes to reduce stigma and discrimination among target groups prioritised by mental health service users in surveys such as Viewpoint and Stigma Shout.

#### **Recommendation 13**

I recommend that the evidence based 'Time to Change' programme should continue to be funded and should continue to involve and empower 'people with lived experience'.

Standards in physical healthcare drive prioritisation, investment, availability of service information and performance. This focus is needed for mental health services – while ensuring the adverse impact of targets is mitigated. The way in which parity levers are implemented should take account of the international clinical evidence base about timescales and processes which will most improve outcomes.

#### **Recommendation 14**

I recommend that NHS England develop a programme of work to agree waiting times and access standards across mental health services, starting with the collection and publication of robust national data to underpin the development and implementation of this programme.

#### Chapter 2

# Public mental health: evidence based priorities

#### **Chapter authors**

Sally Davies<sup>1</sup>, Nisha Mehta<sup>2</sup>

- 1 Chief Medical Officer and Chief Scientific Adviser, Department of Health
- 2 Editor-in-Chief, Annual Report of the Chief Medical Officer 2013, Department of Health

#### Overview

In conducting an extensive scoping exercise for this Chief Medical Officer (CMO) report about public mental health, it became apparent to us that there were several unique issues in this area that require careful framing from the outset. Unlike many other areas of health and medicine, public mental health is a complex field to define because it would ideally embrace notions of both good and poor mental health within its scope. In current usage, it has contested boundaries and terminology, and presents challenges in achieving a common understanding that can be applied in everyday practice by the NHS, government departments and executive agencies, service users, patients and funders, as well as by users of research. In a departure from the format of previous reports, this introductory chapter is additional to the CMO's summary and is co-authored by the CMO and the Editor-in-Chief; it aims to give consideration to these issues and hence to frame the report.

We set this annual report within a broader context, and discuss the environment within which it is sited. This chapter also proposes a framework for advancing a usable understanding of public mental health, drawing upon high-quality evidence. We need clarity of concept and research excellence to form the basis of work going forward.

#### Terminology

There is general agreement among those affected by mental health problems, or working in the field of mental health, that there is no universally acceptable lexicon for or cultural understanding between all the people affected by the experience of mental health problems. The result is that language in this field is particularly contested, revisited and innovated. <sup>1-4</sup> This somewhat unique debate gathered momentum with the growth of the patient movements of the 1970s and 1980s. <sup>5</sup> For example, there are some groups who may, in some circumstances, question legitimately the usefulness of receiving a psychiatric diagnosis. <sup>6</sup> Others fundamentally disagree with the 'medical model' of mental distress, <sup>7,8</sup> although a widely accepted alternative model has not emerged in its place. <sup>5\*</sup>

The power of detention and compulsory treatment for a small minority of people with mental illness conferred by the England and Wales Mental Health Act (1983) contributes to a perceived imbalance of power in mental health care compared with physical health care, further complicating relationships between groups.<sup>9</sup> Recent years have seen the positive development of the concept of mental health activism by contemporary patient groups.

We are fortunate to have a large, active, collegiate and highly valued patient movement in mental health in England. Indeed, it is heartening to see that public mental health in England leads the way in being characterised by government, public bodies, service providers, service user and patient groups, charities and research groups working together in novel and enterprising ways, both at a local and national level. 10–12 Such an approach allows all of those who are active in the field of public mental health to focus constructively together on themes such as advocacy, empowerment, peer support, self-determination, whole-person care, parity of esteem, recovery, positive mental health, consumerism, policy and planning, service provision, monitoring, stigma and discrimination, research and evaluation and more.

The varied landscape of public mental health is clearly a source of great strength. However, it also gives rise to stark differences in favoured nomenclature between different groups, traditions, individuals and practitioners. This makes for a complex field, and one which a careful approach to public involvement in research may help to define in a generally acceptable way in future.<sup>13,14</sup> For the purposes of this report we caveat our chosen use of terminology by acknowledging that there are many different perspectives on this debate and that some groups may disagree with the approach particular authors have chosen to take. However, one of the main functions of the second volume of the CMO's annual report is to present key issues in a specific area of concern in a clear and evidence based manner, in order to make the case for positive change. It is aimed at a wide variety of groups, each of which has different traditions and approaches towards the subject. To achieve greater clarity, we need to use specific, accurate and appropriately precise terminology which promotes maximum cross-sectoral scientific understanding of the population health variations in question.

In building this report, we found that the use of multiple overlapping terms by different groups has the potential to cause confusion about which exactly is the group in question and what exactly is being discussed.<sup>15</sup> Clear and concise nomenclature will also enable more effective mental health intelligence and information gathering, to facilitate the meaningful measurement of progress towards parity of esteem. Expert chapter authors have therefore been asked to use carefully chosen terms as far as possible throughout the report – except when they are referring to specific population groups which have been described in a particular way by the evidence being cited.

We provide our rationale for the preferred terms in this report in Table 2.1. In the first column of Table 2.1 we list the defining features of various subgroups within the population as described by their mental health status. In the second column, we list all the terms used to describe each subgroup that we have encountered in the course of our scoping exercise and review of policy reports and documents, literature from service user/patient groups, academic literature, voluntary sector literature and medical literature. Noting the unwieldy number of commonly used

<sup>\*</sup> The 'medical model', while equated by some with a narrow 'bio-medical' approach to mental health, in reality has much to contribute. Medicine as a discipline spans a broad range of approaches, sciences and social sciences, drawn in equal measure from the 'bio-psycho-social model'. Set within the context of a firmly 'multidisciplinary team' approach, psychiatry and general practice, for example, are ideally placed to contribute to narratives about public mental health.

#### **Public mental health: evidence based priorities**

terms to describe each group and the large amount of overlap between the terms used to describe different subpopulations, in the third column we list our preferred terms for each group for this report. We give details of our rationale for choosing these particular terms in the final column, but generally we support any approach to terminology for which there is a robust tradition of evidence and in which the rationale for the choice of terms is made clear. Some of the terms in this table simply have a greater weight of evidence behind them than others.

Table 2.1 Public mental health: populations, concepts and terminology

Population related to public mental health requiring clarification	Common terminology (from scoping exercise and literature review)	CMO annual report preferred terminology (where possible) or discussion of issues with terminology definitions and metrics	Rationale for chosen terminology and additional information
■ Collective term for a group of people who have been referred to, are currently accessing, have previously accessed or are likely to re-access mental health services (including primary care mental healthcare)	<ul> <li>Patients</li> <li>Service users</li> <li>Users</li> <li>Consumers</li> <li>Customers</li> <li>Clients</li> <li>Ex-patients</li> <li>Survivors</li> <li>Experts by experience</li> <li>People with lived experience</li> <li>People with experience of mental health issues/problems/distress</li> <li>People with a history of mental illness</li> </ul>	<ul> <li>Patients         or</li> <li>Service users</li> <li>Other terms to be used as appropriate in chapters where specific evidence is being described which uses alternative terms</li> </ul>	<ul> <li>There is a lack of evidence of a clear mandate for any term, but some indications that the previously used term 'service user' is no longer commonly preferred</li> <li>In 2013 the Royal College of Psychiatrists reverted to using the term 'patient' instead of 'service user' in official documentation</li> <li>Parity of esteem between mental and physical health is more likely to be facilitated by consistent terminology</li> </ul>
■ Collective term for a group of people who meet ICD-10/DSM-5 criteria for mental disorder(s) but who are not currently referred for or receiving treatment from services (including primary care mental healthcare)	<ul> <li>75% 'treatment gap'</li> <li>People with lived experience</li> <li>People with mental illness</li> <li>People with mental disorder</li> <li>People with psychiatric disorder</li> <li>People with experience of mental health issues/problems/distress</li> </ul>	<ul> <li>People with mental illness who do not receive treatment</li> <li>People with mental disorder who do not receive treatment</li> <li>The mental health treatment gap</li> </ul>	In the absence of a clearly mandated alternative to the medical model of mental distress, the term 'people with mental illness/disorder' will be used to describe this group

Population related to public mental health requiring clarification	Common terminology (from scoping exercise and literature review)	CMO annual report preferred terminology (where possible) or discussion of issues with terminology definitions and metrics	Rationale for chosen terminology and additional information
■ Description of the experience/ defining attributes of a group who meet ICD-10/DSM-5 criteria for mental disorder(s)	<ul> <li>Mental health</li> <li>Mental health problems</li> <li>Mental health illness</li> <li>Common mental disorder</li> <li>Severe mental illness</li> <li>Mental disorder</li> <li>Psychiatric disorder</li> <li>Mental illness</li> <li>Mental distress</li> <li>Mental health issues</li> <li>Rejection of medical model</li> </ul>	<ul> <li>Mental illness</li> <li>Common mental disorder (CMD)</li> <li>Severe mental illness (SMI)</li> </ul>	Estigma and discrimination against people with mental illness is an important reason behind the rise of 'euphemistic' terms to describe mental illness. Euphemisms include 'mental health' when in fact what is meant is 'mental illness'. This results in a problematic lack of clarity when seeking to frame a public mental health debate
■ Description of the experience/ defining attributes of a group who experience some symptoms of ICD- 10/DSM-5 mental disorder(s) but who do not meet the diagnostic criteria for a mental disorder	<ul> <li>Normal</li> <li>Mental health problems</li> <li>Mental health issues</li> <li>Mental health strain</li> <li>Mental health symptoms</li> <li>Temporary distress</li> <li>Mental distress</li> <li>Action of medical model</li> </ul>	<ul> <li>Our preferred terms are drawn from the academic fields for which there is both a robust evidence base and a mandate. The proliferation of poorly defined terms without clear evidence detracts from high-quality work in established fields within public mental health</li> <li>Use specific terms to describe specific populations or attributes</li> </ul>	<ul> <li>This chapter calls for clear descriptions of the populations in question, using specific and scientific public health nomenclature with all conclusions supported by evidence based public mental health research</li> <li>The use of unclear and overlapping terminology in some of the public mental health peer-reviewed, grey and policy literature problematically blurs the lines between emerging research agendas within mental health promotion, positive mental health and well-being on one hand and the more established scientific disciplines of mental illness prevention, treatment and recovery</li> </ul>

Population related to public mental health requiring clarification	Common terminology (from scoping exercise and literature review)	CMO annual report preferred terminology (where possible) or discussion of issues with terminology definitions and metrics	Rationale for chosen terminology and additional information
■ Description of the experience/ defining attributes of a group who experience some or all of the risk factors for ICD-10/DSM-5 mental disorder(s) but who do not meet the diagnostic criteria for a mental disorder	<ul> <li>Normal</li> <li>Mental health</li> <li>Positive mental health</li> <li>Mental capital</li> <li>At risk</li> <li>Recovered/in remission</li> <li>Empowered</li> <li>Adjusted</li> <li>Living well</li> <li>Well-being</li> <li>Flourishing</li> <li>Protective factors</li> <li>Rejection of sociological/psychological constructs - 'unique individual'</li> </ul>	of populations in relation to robust evidence  Avoid interchangeable use of illdefined terms  Use terms with clear definitions and valid metrics	on the other. This results in much of the literature in the field of mental health promotion and well-being using findings from the results of more established disciplines inappropriately as part of an evidence base to which they cannot be said to apply  Therefore the use of overlapping terminology should be discouraged and assertions should stop being made that, by using the evidence base of related disciplines, associations, causality and other conclusions can be drawn for the new areas of mental health promotion, positive mental health and wellbeing. Instead there should be a focus on the incremental building of a high-quality and peer-reviewed evidence base and economic case for clearly defined areas to support and inform future policy and spending

Population related to public mental health requiring clarification	Common terminology (from scoping exercise and literature review)	CMO annual report preferred terminology (where possible) or discussion of issues with terminology definitions and metrics	Rationale for chosen terminology and additional information
a group of people who meet the criteria for positive mental health and positive functioning, irrespective of the presence or absence of diagnosable mental illness, and as measured and reported (as far as is currently possible) by validated measurement scales (not proxy measures)	■ Good/positive mental health ■ Health ■ Well-being ■ The dynamic space of well-being ■ Wellness ■ Positive psychological functioning ■ Flourishing ■ Good/high/present/ increased/more/better levels of: ■ well-being □ hedonic well-being □ subjective well-being □ mental well-being □ psychological well-being □ psychological well-being □ social well-being □ social well-being □ social well-being □ happiness □ life satisfaction □ quality of life □ resilience ■ Rejection of sociological/psychological constructs - 'unique individual' ■ Individual' ■ Health	■ There is a pressing need for widespread agreement across sectors on the definitions of particular terms within this emerging field of research and policy. There is a need to use terms and definitions consistently across the literature to enable useful and comparable scientific study.  ■ There is a need for supplementation of the voluminous grey literature with evidence based and peer-reviewed consensus and clarification on the relationships between the dimensions of health, well-being, mental health, physical health and social functioning. Of particular relevance to the remit of this report, there is a need to clarify the nature of the common ground between positive mental health and well-being and mental illness. There is additionally a pressing need to clarify whether measures of positive mental health and well-being are appropriate for use in populations with mental disorders. This approach should inform high-quality policy and spending decisions. The process should involve all relevant academic disciplines, and should explicitly involve the expertise of the psychiatric, psychometric and quality of life research communities in consultation, collaboration, peer review, research agenda setting and funding decisions.  ■ There is a need for an independent and peer-reviewed review of measures. This should include pre-	■ There is a need for future research to achieve a set of specific, accurate and descriptive metrics for the phenomenon in question. There is a need to achieve an evidence based/validated consensus on whether these measures are scalar or multidimensional, resulting in a position on the appropriate terminology for metrics that should accompany their reporting  ■ There is a pressing need to stop relying on proxy measures from related and more established scientific disciplines and to avoid the damaging practice of inappropriately rebadging' the results of studies from other disciplines as evidence of the quality of the evidence base to justify a policy and funding focus on positive mental health and well-being  ■ For example, evidence of the presence/absence/relative level/quality of well-being in various populations has been suggested in high-profile documents as being measurable by proxy by rolling together multiple and often unrelated outcomes of various studies that form part of the psychiatric or psychological research literature. Examples include:  □ 'difficulties' □ nervousness □ downheartedness □ downheartedness □ maladiustment

Population related to public mental health requiring clarification	Common terminology (from scoping exercise and literature review)	CMO annual report preferred terminology (where possible) or discussion of issues with terminology definitions and metrics	Rationale for chosen terminology and additional information	
Description of the state achieved by a group of people who do not meet the criteria for positive mental health and positive functioning, irrespective of the presence or absence of diagnosable mental illness, and as measured and reported (as far as is currently possible) by validated measurement scales (not proxy measures)	<ul> <li>■ Poor/negative mental health</li> <li>■ III health</li> <li>■ III-being</li> <li>■ Poor psychological functioning</li> <li>■ Languishing</li> <li>■ Languishing</li> <li>■ Poor/low/absent/ decreased/worse levels of:         <ul> <li>□ well-being</li> <li>□ eudaemonic well-being</li> <li>□ subjective well-being</li> <li>□ emotional well-being</li> <li>□ psychological well-being</li> <li>□ affective well-being</li> <li>□ evaluative well-being</li> <li>□ affective well-being</li> <li>□ affective well-being</li> <li>□ affective of life</li> <li>□ happiness</li> <li>□ life satisfaction</li> <li>□ quality of life</li> <li>□ resilience</li> <li>□ resilience</li> <li>□ resilience</li> <li>□ Rejection of sociological/psychological constructs - 'unique individual'</li> </ul> </li> </ul>	existing quality of life measures (see Appendix 1) and a review of commonly used proxy measures from other disciplines (e.g. psychiatry) and their suitability for use in this field.	<ul> <li>□ depression and anxiety</li> <li>□ psychiatric symptoms</li> <li>□ temperament</li> <li>□ personality disorder</li> <li>□ low self-esteem</li> <li>□ suicidal behaviour</li> <li>□ anger</li> <li>□ intense interpersonal relationships</li> <li>□ emotion disaffection</li> <li>□ intense interpersonal relationships</li> <li>□ emotion disaffection</li> <li>□ intense interpersonal relationships</li> <li>□ persistent depressive symptoms</li> <li>□ abandonment</li> <li>□ persistent depressive symptoms</li> <li>□ aver time</li> <li>□ self-reported health</li> <li>□ anxiety yesterday</li> <li>□ bullying, harassment and stress</li> <li>□ there is a pressing need to</li> <li>□ acknowledge the confounding effect of unobserved variables when measuring and reporting outcomes relating to research about positive mental health and well-being. There is a need for much greater robustness in scientifically examining the direction of causation in conclusions relating to positive mental health and well-being theory. There is also a need to avoid superimposing positive mental health and well-being conclusions on epidemiological</li> </ul>	
			evidence where the evidence does	
			of linking the findings to the new	
			research areas of positive mental health and well-being	

## Public mental health in England: the debate

It became clear in scoping this report that, in addition to a discussion about terminology, this introductory chapter also needs to provide a framework for public mental health. We take 'public mental health' to mean a public health or population health science approach to mental health and the mental health variations exhibited by populations. In large part due to the problematic use of euphemistic terminology described in Table 2.1, the field of public mental health is an area characterised by lack of clarity over its boundaries and definitions, although greater consensus may exist about its core versus more recent aspects. We are concerned by the relative lack of consensus in the field over fundamental questions. For example:

- What is public mental health and what are its key components?
- How is it experienced and measured by available tools within population health science?
- What value is placed on it, and is this consistent across society and professional groups?
- How does mental health relate to the rest of a person's life over the life course?
- How do concepts within public mental health relate to one another and to adjacent fields?
- Do we have the right approach to the generation and evaluation of evidence and policy in public mental health in England? If not, how might we do better in future?

We followed this debate closely and heard repeated calls for clarity and quality with regard to terminology, the scientific evidence base and the questions we pose above. We therefore provide here an overview of the issues and contested ground within current public mental health narratives and dialogues, and seek to build a more robust, evidence based consensus to inform future work in the field.

#### Public mental health: a World Health Organization framework

The conceptual issues described above are not limited to public mental health in England. Over the last decade, the Department of Mental Health and Substance Abuse at the World Health Organization (WHO) has incrementally built a helpful model for conceptualising public mental health in a global context, which has most recently been incorporated into the WHO's Mental Health Action Plan 2013–2020. 16,17 We summarise the WHO approach to public mental health here, before considering the ways in which it might inform the development of a useful framework for public mental health in England.

The WHO has defined health as 'a state of complete physical, mental and social well-being and not merely the absence of

disease or infirmity'.¹8 In 2001, the WHO described mental health as 'a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community'.¹9

Although this is a helpful start, further evidence and conceptual clarity were clearly needed. In response, the WHO published two key reports about the prevention of mental disorders (2004)<sup>20</sup> and promoting mental health (2005),<sup>21</sup> in which they recognised three ideas central to the improvement of health:

- Mental health is an integral part of health.
- Mental health is more than the absence of illness.
- Mental health is intimately connected with physical health and behaviour.

This message echoes current policy priorities for mental health care in England and the key messages in this report: namely that the organisational and conceptual division between physical and mental health is a barrier to the improvement of health more generally.

The 2004 WHO Prevention of Mental Disorders report further recognised that:

An initial difficulty faced by researchers and policymakers in this field is related to the similarities and boundaries between the concepts of mental health and mental illness and between prevention and promotion.<sup>20</sup>

This message echoes the difficulties we have outlined in Table 2.1 and underlines the need for definitional and conceptual clarity about the subjects in question to inform clear and effective evidence generation and subsequent policy making.

The 2005 WHO Promoting Mental Health report additionally observed that:

Mental health and mental illness by and large are viewed as residing outside the public health tradition with its fundamental concepts of health and illness as multifactorial in origin (Cooper 1993) and of there being a continuum between health and illness (Rose 1992).

The Promoting Mental Health report argued that this compromised the field of public mental health, meaning that opportunities for promoting mental health were missed and efforts to reduce the burden of mental illness focused mainly on the treatment of ill individuals. These issues were perpetuated by the euphemistic use of the term 'mental health' to describe matters related to mental ill health (which we have attempted to clarify in Table 2.1), which was causing damaging confusion regarding the relationship between mental health and mental illness. Furthermore, the physical separation of physical and mental health care systems and the chronic nature of some mental disorders contributed to an image of mental illness as 'incurable', with little scope for mental health promotion.

#### **Chapter 2**

The WHO suggested instead that:

The twin aims of improving mental health and lowering the personal and social costs of mental ill-health can only be achieved through a public health approach. Within a public health framework, the activities that can improve health include the promotion of health, the prevention of illness and disability, and the treatment and rehabilitation of those affected. These are different from one another, even though the actions and outcomes overlap. They are all required, are complementary, and no one is a substitute for the other.<sup>15</sup>

The Promoting Mental Health report expands on this further, identifying that mental health promotion is primarily concerned with the determinants of mental health, and that mental illness prevention is concerned with the causes of disease. The WHO's key messages for mental health promotion and mental illness prevention are summarised in Tables 2.2 and 2.3.

# Table 2.2 Mental health promotion – adapted from the WHO approach

Definition	Measurement and metrics	Challenges	Evidence base – key issues
Mental health promotion activities imply the creation of individual, social and environmental conditions that enable optimal psychological and psychophysiological development. Such initiatives involve individuals in the process of achieving positive mental health, enhancing quality of life and narrowing the gap in health expectancy between countries and groups. It is an enabling process done by, with and for the people	Elements of positive mental health are drawn from many diverse disciplines and are not the preserve of one approach  There is a need to acknowledge that subjective measurement approaches towards positive mental health may not be consistently applicable across all groups, especially groups with mental illness  Unification of concepts, evidence and practice through the development of indicators is essential. The selection of indicators should be systematic and logical  Selected scales and indicators should be robust and validated for the measure in question. Proxy measures should not be used	Broad concepts should be broken down into working definitions to be used when drawing up the aims of interventions. It is also useful to distinguish between interventions that have the primary goal of improving the mental health of individuals and populations and those which enhance mental health as a side benefit.  A cross-sectoral approach is needed due to the relationship between social and economic factors and mental health.	A high-quality evidence base is essential to build credibility – specific evidence based proposals with measurable outcomes are required  Suggested methods to build an evidence base include aetiological research to link mental health with its critical determinants, with evaluation of changes in the same determining or mediating variables; and work to develop indicators of determinants and to quantify the mental health benefits of changes in the face of complex interactions  Barriers to evaluation include the following: complex evaluations have long lead times compared with short policy-making windows; experimental evaluations can be ill-suited to answering policy questions; and effects are small and widely distributed, necessitating large sample sizes  High-quality mental health impact assessment and economic evaluation are important. High-quality evaluative evidence needs to provide information on the nature, size and likelihood of predicted mental health impacts.  Qualitative data must be of high quality and should inform understanding of the existence and nature of find mechanisms for) the outcomes of interventions. Longitudinal life course data need to be supplemented by specific longitudinal studies to prove or disprove hypotheses relating to observed relationships  Cross-disciplinary agreement about the hierarchy of evidence is vital. Evidence should be of the highest possible standard and judged on criteria from the relevant paradigm
			Evidence to policy: policymakers should make greater use of scientific knowledge before proceeding. For example, they should screen policy interventions to ensure that their effects meet a minimal set of evidence based requirements

# Table 2.3 Mental illness prevention – adapted from the WHO approach

Definition	Measurement and metrics	Challenges	Evidence base – key issues
Mental disorder prevention aims to reduce the incidence, prevalence and recurrence of mental disorders, the time spent with symptoms and the risk conditions for mental illness, preventing or delaying recurrences and also decreasing the impact of illness in the affected person, their family and society	Measurements are defined depending on the prevention strategy in question Indicators, scales and outcomes should be robustly designed, validated and evaluated	Mental disorders have multiple determinants, and prevention needs to be a multi-pronged effort as part of a bio-psycho-social approach. An understanding of the relationship between mental and physical disorder is needed to inform policy.  Effective prevention requires inter-sectoral linkages. An approach to prevention should include: needs assessment and programme development; dissemination and adoption; adaptation and tailoring; implementation; evaluation and monitoring; and sustainability.  Conditions for prevention include:  a national policy for mental disorder prevention and mental health promotion within the context of public health and public policy. Prevention policies should be population oriented and should embrace different settings across the life course capacity building and training for prevention and promotion at national and local levels  research and advocacy – based only on the highest-quality evidence  resources and infrastructure that promote sustainable programmes and policies.  Sustainable and effective collaboration between organisations is also needed	The need for evidence: there is a pressing need for accountability in public spending to implement preventative measures that are cost effective, sustainable and publicly credible. This is especially important at the stage of large-scale funding, dissemination and implementation  Standards of evidence: solid standards are needed to avoid invalid conclusions on the outcomes of intervention trials (internal validity) or on the expected outcomes of such interventions when they are implemented in different sites and settings (external validity). In the interest of the targeted population, evidence should meet the highest possible standards Martialling the evidence: consider grouping the evidence – for example, 'macro-level' strategies, reducing stressors and enhancing resilience; prevention of specific mental disorders  Knowledge of evidence of effectiveness needs further expansion: further efforts are needed to expand the spectrum of effective preventation interventions, to improve their effectiveness and costeffectiveness in varied settings and to strengthen the evidence base. This requires repeated evaluation of programmes and policies and their implementation. Knowledge of strategies, programme characteristics and other conditions that have a positive impact on effectiveness should be translated into guidelines for the improvement of programmes for the implementation should be guided by available evidence: ethically, and to make optimal use of the limited resources, funding should be made available for preventative programmes and policies that show scientific evidence of their effectiveness

Drawing upon the component parts of public mental health outlined in Tables 2.2 and 2.3, the WHO emphasised the need to bring them together, along with treatment and rehabilitation for those with mental disorder. The WHO argued for a coherent and unified public mental health policy approach:

Mental health policy is an organized set of values, principles and objectives for improving mental health and reducing the burden of mental disorders in a population. It outlines a vision for the future and helps to establish a model for action. When well formulated, mental health policies also identify and facilitate agreements for action among the different stakeholders in the mental health field and designate clear roles and responsibilities. Without policy direction, lack of coordination, fragmentation and inefficiencies in the system will weaken the impact of any mental health intervention. <sup>15</sup>

In 2013 the WHO followed up on this work with the publication of the Mental Health Action Plan 2013–2020, in which the concepts of mental health promotion, mental illness prevention and treatment and rehabilitation were incorporated into a clear road map for global mental health in the remainder of the decade. The overall goal of the action plan is stated as:

... to promote mental well-being, prevent mental disorders, provide care, enhance recovery, promote human rights, and reduce the mortality, morbidity and disability for persons with mental disorders.<sup>17</sup>

The action plan has four objectives (see Box 2.1) and relies on six cross-cutting principles (see Box 2.2). It draws together the constituent components of public mental health and their metrics to allow progress to be monitored clearly and closely. The action plan clearly emphasises the need for robust scientific evidence to form the basis of mental health strategies for treatment, prevention and promotion, as well as highlighting the need to take cultural considerations into account. It helpfully identifies the main strengths in the evidence base that we already have for mental health promotion and mental illness. It also highlights the benefits of intervening to prevent mental illness early in the life course; of early identification and treatment of mental disorder in children and young people: of interventions to reduce stigma and discrimination and to increase mental health literacy; of the reduction of violence; and of suicide prevention. In short, it is a critically important resource for England as we consider our own approach to public mental health activities.

#### Box 2.1 WHO Mental Health Action Plan 2013–2020: key objectives

- 1. To strengthen effective leadership and governance for mental health
- 2. To provide comprehensive, integrated and responsive mental health and social care services in communitybased settings
- 3. To implement strategies for promotion and prevention in mental health
- 4. To strengthen information systems, evidence and research for mental health

#### Box 2.2 WHO Mental Health Action Plan 2013–2020: cross-cutting principles

- 1. Universal health coverage
- 2. Human rights
- 3. Evidence based practice
- 4. Life course approach
- 5. Multi-sectoral approach
- 6. Empowerment of persons with mental disorders and psychosocial disabilities

#### Public mental health in England

With the WHO framework providing a contextual backdrop, we turn to the present state of the field of public mental health in England, and eventually to a future perspective. We discuss the contemporary policy and political context within which this is situated, and we seek to clarify some of the definitional and methodological problems with the concept, as identified in Table 2.1. This has taken us into the emerging field of 'well-being' in so far as it is a population science that relates to public mental health and extends or integrates with it. To clarify some of these boundaries, we propose a model for the understanding of public mental health and well-being. Our approach is based upon independent scientific analysis and appraisal of the quality of the evidence base, as well as the content of key propositions. Our model draws upon the WHO framework discussed above, has been shaped by expert consultation during this report's cross-sectoral scoping exercise and has benefited from extensive peer review. Our aim is to acknowledge and welcome the progress that has been made by colleagues across sectors in striving to understand and improve the nation's mental health and well-being. However, our role is also to highlight areas in

which a more scientific approach to the complex subjects in question is urgently needed to enable both high-quality expansion and integration of the evidence base, and a sustainable, economically effective policy approach to public mental health and well-being during challenging economic times.

### The Foresight Report (2008), 'Mental Capital and Wellbeing: Making the most of ourselves in the 21st century'

The current level of political and policy interest in the field of public mental health in Britain received its most recent impetus from the publication of the Foresight Report in 2008.<sup>22</sup> This built on existing theories and was the result of an independent project which aimed to develop and articulate a vision for:

The opportunities and challenges facing the UK over the next 20 years ... and the implications for everyone's "mental capital" and "mental wellbeing".

What we all need to do to meet the challenges ahead, so that everyone can realise their potential and flourish in the future.

'Mental capital' was defined as:

'a person's cognitive and emotional resources, including cognitive ability, how flexible and efficient they are at learning ... 'emotional intelligence' such as social skills and resilience in the face of stress'.

'Mental wellbeing' was defined as:

'a dynamic state, in which the individual is able to develop their potential, work productively and creatively, build strong and positive relationships ... and contribute to their community'.

Promoting positive mental health and well-being was a key message of the Foresight Report, which hypothesised that

'achieving a small change in the average level of wellbeing across the population would produce a large decrease in the percentage with mental disorder, and also in the percentage who have sub-clinical disorder (those "languishing")'.

The Foresight Report concluded with a call for a 'strategic and visionary approach' to mental capital and well-being, underpinned by a strong evidence base using randomised controlled trials, better economic analyses of interventions and improvements to cross-government action and central co-ordination.

# Well-being and public mental health: an evidence and policy framework

As a next step, Foresight commissioned the report *Five ways to wellbeing*, which was published in 2008 by the New Economics Foundation (NEF). The report made five suggestions for individual action: 'Connect ... Be active ... Take notice ... Keep learning ... Give'. These five recommendations are widely cited as 'drawing on an extensive evidence base of "what works"'.<sup>23</sup> However, the NEF report itself noted that:

... there is little epidemiological evidence examining measures and determinants of well-being. Furthermore there has been greater prevalence of cross-sectional studies in the literature, which do not look at well-being among the same individuals across long time periods ... Confidently asserting causality is, in most cases, difficult. More recent studies have begun to look at the effectiveness of specific interventions on the promotion of well-being ... It should also be noted that there is very little literature, if any, on effect sizes ... Therefore, it is difficult to specify and compare the impact of different actions on the promotion of well-being. 24

Foresight's well-being agenda has been incorporated into several policy areas within mental health. For example, Objective 1 of the Department of Health report *No Health without Mental Health* (2011) is:

More people will have good mental health. More people of all ages and backgrounds will have better wellbeing and good mental health. Fewer people will develop mental health problems – by starting well, developing well, working well, living well and ageing well.

And in 2013, Public Health England set out a vision for the integration of well-being and health that promotes a well-being approach to public mental health through a programme of activities targeted at the public health system. <sup>25,26</sup>

In policy terms (within the world of public mental health), the stage was set for the promising new and exciting concept of wellbeing to revolutionise the way in which we approach the mental health of populations. A necessary concurrent step in the ascendancy of well-being in research and policy was an effort to build a robust evidence base to support this evolving field, but on clear and agreed definitions. We turn next to a critical appraisal of the evidence to date. Our focus in this report is firmly on the evidence for a well-being approach as it relates to public mental health. However, given the holistic and cross-governmental nature of the concept of wellbeing, coupled with the widespread lack of consensus over definitions and boundaries as shown in Table 2.1, a more general discussion about 'well-being evidence' and 'public health' is necessary in places to supplement the discourse.

## Approaches to defining and measuring well-being

Since 2008, 'well-being' research narratives and policy discourse have expanded exponentially. At the same time, there is a rising tide of calls for better definitions of well-being that go beyond merely an 'account or description' of well-being itself, towards a 'clear and definite statement of the exact meaning of the term'.<sup>27</sup> Several different, often

interrelated, disciplinary approaches with potential relevance for 'well-being' are recognised and debated in the literature, and we outline these in Table 2.4.

Table 2.4 Disciplinary approaches with potential relevance for well-being: a summary

Discipline	Related and interrelated concepts
Medicine	<ul> <li>Psychiatry (social networks, social support, inequalities, stigma and discrimination and their effect on mental health)</li> <li>The 'bio-psycho-social model'</li> <li>Social and psychological prescribing</li> <li>Medical psychotherapy</li> <li>Genetics (gene-environment interactions, epigenetics)</li> <li>Neurobiology (the impact of stressors on brain anatomy, biological determinants of positivity)</li> <li>Developmental psychopathology</li> <li>Patient satisfaction/patient-reported outcome measures</li> <li>Health-related quality of life</li> </ul>
Philosophy (humanism or existentialism)	<ul> <li>Happiness</li> <li>Self-acceptance</li> <li>Environmental mastery</li> <li>Autonomy</li> <li>Purpose in life</li> <li>Personal growth</li> <li>Positive relationships</li> <li>Engagement with the existential challenges of life</li> <li>Buddhism: focus on the positive; acceptance and compassion for self; mastery of fear, aggression, envy and pride</li> </ul>
Psychology	<ul> <li>Positive psychology</li> <li>Social acceptance</li> <li>Social contribution</li> <li>Social coherence</li> <li>Social integration</li> <li>'Flow' (similar to the meditative state)</li> <li>Signature strengths</li> <li>Set point theory</li> <li>Emotional intelligence</li> <li>Emotional literacy</li> </ul>
Social science	<ul> <li>Economics (utility, happiness, life satisfaction)</li> <li>Quality of life</li> <li>Life satisfaction</li> <li>Social capital</li> </ul>

It seems clear from the outset that 'well-being' means different things to different people. Each approach has inherent strengths and weaknesses, but one thing is obvious: there is no clear consensus on the best way to define and measure well-being within mental health. In 2008, Dolan et al. reviewed the economic literature on factors associated with subjective well-being and identified 'a range of problems in drawing firm conclusions about the causes of subjective well-being; these include some contradictory evidence, concerns over the impact of the findings of potentially unobserved variables and the lack of certainty on the direction of causality'. <sup>28</sup> In 2009, the Office for National Statistics (ONS) wrote that well-being is 'intangible, difficult to define and even harder to measure'. <sup>29,30</sup>

In 2011, Forgeard et al. observed that the lack of clarity in this regard 'has given rise to blurred and overly broad definitions of wellbeing'.<sup>31</sup> In a recent report from NatCen Social Research that analysed longitudinal trends in subjective well-being, one of the key findings was the difficulty of 'untangling cause and effect – many associations between predictive factors – like relationships, environment and health – and subjective well-being will be better understood when more longitudinal data on this topic is available'.<sup>32</sup>

As we discuss next, when this is combined with contested boundaries (particularly within public mental health) and the widespread use by researchers and policymakers of an array of validated, unvalidated, subjective and objective measurement approaches and 'proxy scales' of varying lengths and sophistication,<sup>33</sup> it can become difficult to scientifically examine any single well-being perspective in a robust and consistent way for public health policy in general, and public mental health policy in particular. Contrasting two perspectives appears harder still, and yet is of theoretical and practical importance. One contemporary and potentially informative approach which might have direct relevance for the future of public mental health is that taken by the ONS, to which we turn next.

# Well-being and public mental health: the ONS approach

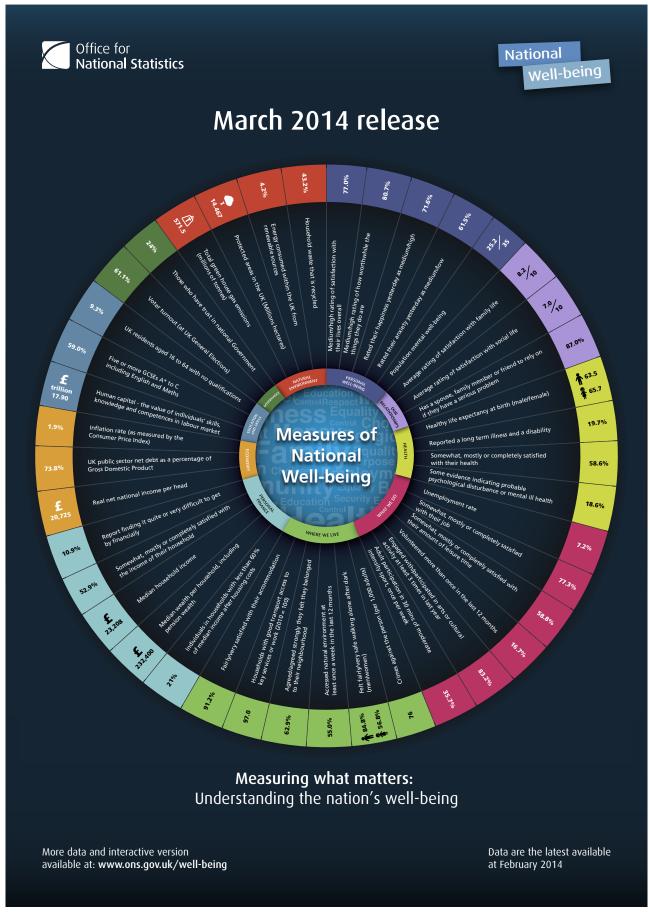
In 2010 the Prime Minister, David Cameron, tasked the ONS with measuring 'national wellbeing'. The aim was to provide a robust underpinning to inform a new focus on measuring the nation's progress by indicators of 'quality of life', rather than relying solely on gross domestic product and 'how our economy is growing'.<sup>34</sup> The Prime Minister emphasised that this new policy focus was not a distraction from economic recovery; nor was it beyond the remit of government to try to influence national well-being. The Prime Minister called for a national debate about how to 'build a better life' and a reappraisal of 'what matters', arguing that this was more than just 'the bottom line'. This was an excellent start and, over the following six months, the ONS consulted extensively across the nation, asking the public what they thought mattered.<sup>35</sup>

Starting with the findings of this consultation exercise, the ONS has now developed and refined a framework assembling diverse indicators of well-being that might assist the ambition of national measurement, reporting and monitoring. This framework consists of 10 'domains' and 41 'headline measures', some of which are intrinsically subjective and some more objective. The results for each measure under the domains are incorporated into an interactive 'wheel of measures' (Figure 2.1), published as part of a series of annual reports, international comparisons and detailed domain-specific reports analysing the data collected as part of the Measuring National Well-being Programme, <sup>36</sup> combined with contextual findings from other national surveys. Thanks to this approach, we now routinely assemble data on multiple topics, such as:

- our relationships
- health
- what we do
- where we live
- personal finance
- the natural environment
- the economy
- education and skills
- personal well-being
- governance.

The data and indicators within these domains are expected to have relevance across both national and local government, and will increasingly provide us with a longitudinal, multi-component perspective on 'what matters' to people, as defined by consultation and continually refined and interrogated online. The Cabinet Office pulls this impressive work together and leads the way with a drive to encourage a wide range of policymakers across government departments and sectors – not traditionally involved in work of this kind – to consider a well-being approach within their own particular domain, informed by new indicators and potentially new metrics from the increasingly refined data available from the ONS.

Figure 2.1 The ONS 'Measures of National Well-being'



Source ONS

# **Chapter 2**

A key domain within the Measuring National Well-being Programme is that entitled 'Health'. During the ONS 'national debate', when people were asked what things in life mattered and what should be reflected in the measures of national well-being, 'health' was most commonly cited.<sup>37</sup> The 'Health' measures in the programme include:

- healthy life expectancy at birth
- reported a long-term illness and a disability
- somewhat, mostly or completely satisfied with their health
- some evidence indicating probable psychological disturbance or mental ill health.

It is outwith the remit of this report to discuss the relationship between health and well-being more generally. However, we now turn to the question of the relationship between mental health, mental illness and well-being by taking a closer look at the ONS approach to the subject.

The most recent 'Health' report from the ONS focuses on population measures of 'satisfaction with health', alongside established guestionnaires on 'evidence of mental ill health'. The General Health Questionnaire 12 (GHQ-12) is used: the GHQ is an internationally validated screening (case finding) measure employed in the general and healthcare populations.38-41 Among groups with high scores on the GHQ there is an increased likelihood of a currently diagnosable common mental disorder (such as anxiety or depression). The GHQ items (when administered in 12, 28 or 30-item short forms) do not establish the presence of a clinical diagnosis, but provide evidence based logic for further evaluation by a healthcare professional trained in the evaluation of symptoms of psychiatric disorder. The ONS has analysed the relationships between satisfaction with health and evidence of mental ill health from such 'screening measures', for example in the findings of their 'Understanding Society' survey.<sup>42</sup> Key findings of relevance to public mental health include the following:

- 'Some evidence of anxiety and depression occurred in a higher percentage of those who were divorced or not in paid work or dissatisfied with their health or who were caring for someone else in the household or were living on their own.'
- 'About 14% of those who reported no limitation in moderate activities showed some symptoms of anxiety or depression compared to 26% of those with a little limitation and nearly 41% of those with a lot of limitation.'

In 2012, the ONS published a 'Health' report<sup>43</sup> in which it supplemented its own measures of 'evidence of mental ill health' with a discussion of the findings of the Adult Psychiatric Morbidity Survey – this has been completed three times to date. This 2012 report included a brief discussion of other measures that can be used to assess 'mental and psychological well-being'. According to the report, both the GHQ-12 and the Warwick Edinburgh Mental Well-being Scale (WEMWBS) should be considered. WEMWBS is a 14-item scale developed specifically with positively worded statements as items, which attempts to cover the key elements of

subjective well-being and happiness (often referred to together as 'hedonic well-being') and the elements of psychological well-being (often referred to as 'eudaemonic well-being', thought to lie beyond hedonic well-being and incorporating more evaluative notions than experienced pleasure) over the preceding two weeks.

The 14-item WEMWBS scale has now been incorporated into national surveys – including the Health Survey for England and the Scottish Health Survey – and a sufficiently large number of studies have used it for generalisable statements to be made regarding its reliability and potential validity. <sup>44</sup> To date, analyses of survey data incorporating both of these measures have reported a strong negative correlation between WEMWBS and GHQ-12. <sup>43</sup> In WEMWBS validation publications, GHQ-12 was moderately negatively correlated with WEMWBS, <sup>44,45</sup> at a level indicating both overlap and distinctiveness.

Attractive though they are, correlational analyses of scale scores cannot document their common measurement/ morbidity range or the levels of any population continuum at which one measure diverges (adds value) or overlaps (converges) with any other. Without sophisticated psychometrics, it is unclear what this tells us about the potential to define a single continuum of mental health variation in the general population which would be of pragmatic utility to public mental health. It has been suggested in a recent report by NatCen<sup>32</sup> that they align (measure the same thing) quite well, or that they might also overlap considerably over the majority of their measurement range. However, they are also promoted as quite different in the same report.<sup>†</sup>

We hope that psychometric work is in progress to clarify these unresolved questions or to further open up the debate over metrics, and if not this should be a priority for research in the field of well-being and mental health.

Greater insight will likely emerge from joint analysis not of scales, but at item level, with other candidates also considered in a similar fashion (e.g. the WHO-5 Wellbeing Index, <sup>46</sup> or even the EQ-5D as a point of reference or distinction for health economists). <sup>47</sup>

Fundamentally we need a reproducible psychometric evidence base, not one divided by use of any particular instrument: we need to know how these metrics relate across populations in terms of their joining points, their measurement range,

<sup>†</sup> In the 'Health' section of Predicting National Well-being (NatCen, 2013), it is stated that 'subjective wellbeing had a very strong association with different indicators of mental ill health'. The results included the statement: 'Among men, presence of mental ill health was very strongly associated with subjective wellbeing. Those with a GHQ score of 4 or more had a linear coefficient of –10.25 for positive wellbeing suggesting that the GHQ and the WEMWBS are very closely, inversely correlated' (page 73). This implies that the metrics overlap considerably over the majority of their measurement range. However, in the same report, under a bullet point just below, they are promoted as quite different: 'It is important to note that subjective wellbeing is not simply the absence or opposite of mental illness, but the presence of positive mental attributes and traits' (page 74).

# Public mental health: evidence based priorities

and also with respect to thresholds. Put simply, we do not yet understand how to interpret the information captured by these different tools in different populations. Can we build bridges between them? What do they span? What lies beneath them? Should they be combined? At what points do they diverge? How do they relate longitudinally?

The GHQ item set, however deployed as the long, midlength or short version, was designed and has been shown to operate as a robust 'case-finding measure/screen' that is valid for case detection in populations, since strata of sum score values identify a relevant 'risk group'. The short versions of these tools do not offer accurate estimates of personal mental health status. Psychometric theory makes it clear that a longer measure is required to reduce uncertainty at the individual level to a degree such that accurate statements can be made about personal levels of mental health for individuals.<sup>48</sup> This is probably the most misunderstood aspect of population health psychometrics, and the lack of understanding in of this aspect, amongst those who have promoted new measures has a lot to do with the uncertain state of affairs in relation to well-being as a population health science.

The GHQ item pool (particularly the 30-item instrument) contains a considerable number of items which were intentionally positively phrased, but this design feature was not introduced in order to measure any aspect of 'positive mental health'. The positive wording was simply there to balance the instrument in terms of item phrasing. This design feature may have given rise to a small potential for measurement of positive mental health, but this would not be an optimal way of doing it: it was not designed for this, nor validated against any such notion. However, the known strata created by GHQ scores might be nuanced further by modest design improvements in order to usefully extend its range for population-wide mental health measurement, but this work has never been commenced; instead, new measures came forth (WEMWBS and the 'shortened' sWEMWBS). These did not build on legacy instruments, nor join with them; instead they were promoted with the vigour of new innovations, and are only safe to use in isolation when there are no concerns about the mental health status of low scorers.

The issue of how psychiatrically distressed low WEMWBS scorers are in terms of likely GHQ morbidity levels has not received any attention, yet it probably reflects the most important omission to date. It should be possible to establish quite rapidly, and with supporting clinical data, whether the endorsement of WEMWBS item responses signifying low well-being (across multiple items) can also be evaluated as a depression screen over its lower score range. This is an urgent need, since well-being narratives would not immediately address this.

Therefore we note with some concern that the online NHS well-being self-assessment tool 'How Happy Are You?'‡ (which uses the WEMWBS scale) informs those who score

'much lower than most people typically score' that there are 'five evidence-based steps we can all take to improve our mental well-being: Get active; Connect with others; Keep learning; Be aware of yourself and the world; Give to others'. We have already discussed the lack of robust evidence for the 'Five Ways to Well-being'. Furthermore, if WEMWBS is proved to be measuring disorder over its lower range, this advice could be regarded as unhelpful at best and frankly dangerous at worst.<sup>49</sup>

It is useful and important that the GHQ items were included in the British Household Panel Survey from 1991 to 2008, and also in its successor 'Understanding Society' from 2009 to 2010. It has often proven tempting for researchers who do not fully understand the GHQ's nuances as a population health screening instrument, or its latent structure, to try to argue that the wording of the items can separate something more 'well-being -like' from something conventional (in terms of mental ill health). Hence the GHQ-12 is partitioned or scored as a 'two factor model', and can be argued to measure both positive and negative mental health.<sup>50</sup> This belief is often accompanied by simplistic notions of reverse scoring items to measure well-being. 33,51 These attempts do not, however, establish a robust longitudinal 'wellbeing' dataset that might be secondarily analysed, since this manoeuvre does not independently operationalise a validated notion of well-being.

Pulling all of this together, we can conclude that the GHQ-12, because it has been robustly validated as a population measure of likely psychiatric caseness, does not measure any a priori notion of well-being. To do this it would need additional new items, or perhaps even a new dimension. Although the inclusion of positively phrased items in the GHQ (and other instruments) appears to offer scope for measuring something positive,<sup>52</sup> this is not necessarily the case. The only combination that may contribute in this way (again, accidentally) is positive responses to the positive questions. However, the evidence accumulated for this view is not yet strongly validated across studies.<sup>53</sup> We suggest, upon reviewing the available evidence, that the scope for measuring any 'upper reaches' of population well-being is unlikely to be achievable without the development of additional items and/or extension of the current GHQ continuum. If this is indeed the case, then clearly new narratives will need to follow that accurately portray this.

Combined use of more items or instruments, such as the pairing of WEMWBS and the GHQ, is to be encouraged, but only in order to establish to what extent they add value to each other in documenting and communicating a full account of population mental health variations and dimensions. This must be seen as central to the future advancement of public mental health as a discipline. The evidence to date suggests that mental health screening scales and well-being instruments are not polar opposites, but correlate negatively to different degrees in different samples; and mental illness and well-being appear to be related but in which populations they diverge or converge is not understood. Typically, populations have not been unmixed into groups

<sup>‡</sup> www.nhs.uk/Tools/Pages/Wellbeing-self-assessment.aspx

with different profiles, for a nuanced understanding to be unveiled. Instead, what is reported is the aggregate: interpreting the aggregate in a heterogeneous setting cannot reveal the diversity that should inform policy and practice.

Current reports from studies that use these measures contain some interesting findings, but further evidence is needed to answer the logical but difficult definitional, correlational and measurement questions that arise from the observations. In the absence of this information, it is necessary to appropriately caveat research that describes positive mental well-being. There is additionally a clear risk that the evidence base for mental well-being is being built on shifting sands because the two scales may or may not exist on a continuum. It is entirely possible to have a mental illness but to simultaneously enjoy high levels of subjective well-being – and vice versa. On the other hand, as thoughtfully discussed in some detail in the World Happiness Report 2013:

Mental illness is one of the main causes of unhappiness. This is not a tautology ... people can be unhappy for many reasons ... but ... chronic mental illness is a highly influential cause of misery.<sup>54</sup>

This confusion about the exact nature of the relationship between mental illness and mental well-being is also apparent within the 'Personal Well-being' domain of the ONS 'wheel of measures'. The ONS has included four subjective measures of the personal well-being of individuals in its Annual Population Survey since 2011 (see Box 2.3). A fifth measure (the seven-item short form of WEMWBS) was added in 2013. We understand that the 'Personal Well-being' domain was originally scoped to include a person's feelings about their own well-being.

However, as with the use of the GHQ-12, the inclusion of the item 'how anxious did you feel yesterday?' as a measure of personal well-being may inadvertently result in further blurring of the boundaries between mental illness and mental

#### Box 2.3 ONS questions on personal wellbeing (from 2011)

Answers are requested on a scale of 0 to 10 where 0 is 'not at all' and 10 is 'completely'.

- Overall, how satisfied are you with your life nowadays?
- Overall, to what extent do you feel the things you do in your life are worthwhile?
- Overall, how happy did you feel yesterday?
- Overall, how anxious did you feel yesterday?

well-being before these relationships have been scientifically defined. High subjective 'anxious yesterday' scores may apply to individuals from a variety of population groups with varying degrees of mental health and/or diagnosable mental illness. By simply including 'anxious yesterday' as a measure

of personal well-being, the resulting 'noise' from true mental illness – which we should not assume is the polar opposite of 'mental well-being' – becomes impossible to distinguish in analysis of such data. The difficulties inherent in this approach are exemplified in one of the key conclusions drawn from the regression analysis in the 2013 ONS report *Measuring National Well-being – what matters most to Personal Well-being*:

People's sense of choice and contentment with their situation appears to be associated with personal well-being. For example, people who are employed but want a different or additional job have lower levels of personal well-being (including higher 'anxious yesterday' levels) than employed people who are not looking for another job.<sup>55</sup>

We suggest that 'anxious yesterday' and other subjective and potentially morbidity-focused measures will not be particularly helpful in measuring subjective personal well-being until we have a much clearer understanding of the boundaries, metrics and relationships between mental well-being and mental illness (as outlined above and in Table 2.1). Collection of 'anxious yesterday' data may be useful to a degree in helping to inform this understanding, although obviously using data from diagnostic scales for mental illness would be the most scientifically robust way to investigate the issue. As the WHO put it in 2009:

What is the meaning of sadness, anger, hopelessness or anxiety in specific situations? In particular, they raise questions about appropriate promotion, prevention and treatment strategies for affective problems and disorders. They are also important in how we define positive mental health and the meaning we give to the absence of positive mental health.<sup>56</sup>

In the absence of a coherent and integrated psychometric evidence base to enable us to answer these questions, we suggest that it may be pragmatic to continue to measure and describe national mental well-being using specific measures (such as the shortened WEMWBS as one indication of personal (subjective) mental well-being) that were developed with such approaches in mind. However, more integration from multiple measurement scales may be of more practical and cumulative scientific value. Notably, this is not the same perspective advocated in a recent NatCen report, *Predicting Wellbeing*, which states:

... measures of mental ill health or functioning such as the Short-form (SF), the General Health Questionnaire (GHQ), or the revised Clinical Interview Schedule (CIS-R) are not included in this review. There is already an established evidence base for what factors predict these outcomes. Furthermore, they are not specifically measures of positive subjective wellbeing, which is the focus of this report.<sup>32</sup>

# Well-being and public mental health: examining the evidence base

The ONS was frank from the outset about the difficulties of defining and measuring well-being. In 2011 the National Statistician wrote:

Overall, the different themes and points of view expressed in the debate reinforce the view that wellbeing – both national and individual – is a complex, multi-dimensional issue. This is consistent with … earlier work on well-being and with ONS's review of existing theories and frameworks of well-being. The review highlighted that there is no clear definition of well-being and that it is a broad term that covers a range of things.<sup>35</sup>

Appropriately caveated, the ONS approach to well-being and mental health is a helpful starting point for building robust data from new items to inform further research and policy work in the area within specific government departments. Their items still need further validation in relation to established or emergent measures (validation is a continual process, after all).

As we have discussed, both well-being and public mental health are relatively new concepts, and we strongly support the WHO in calling for the careful and incremental building of a robust evidence base in this area to ensure credibility and value for money. We have therefore found it helpful to take a closer look at the quality of the evidence base for well-being within public mental health, and have found a great need for detailed insights. Later in this chapter we bring together all the issues inherent in this debate and offer an alternative theoretical framework to underpin the building of a scientifically robust evidence base that relates well-being to specific, defined elements of public mental health as laid out by the WHO.

# Well-being and public mental health: definitions and metrics

The widely accepted use of the disease-focused GHQ-12 to measure mental well-being may have contributed in part to the problematic lack of clarity in terminology within public mental health that we have identified. An approach to mental well-being which incorporates measures of mental illness may have inadvertently spawned an agenda in which terms describing very different populations within public mental health are used interchangeably across different disciplines, despite the lack of validity in some of the claims. The result is inconsistent blurring of the boundaries between population approaches to positive mental health promotion, prevention of mental illness and treatment and rehabilitation of those with mental disorder, often with little apparent thought given to the interrelated concepts in question (as carefully outlined by the WHO and summarised in Tables 2.2 and 2.3). This in

turn has resulted in much of the summary literature covering the field of mental health promotion and mental well-being inappropriately describing the results of intervention studies and trials in the more established field of psychiatric research into prevention and treatment of clinical disorder as part of a 'well-being' evidence base, to which they cannot scientifically be said to apply (see Table 2.1).

The measures used may well be validated for a particular area within psychiatric research, but they are non-valid and unreliable for measuring well-being. This results in 'proxy' outcomes being unscientifically rebadged as 'well-being' outcomes, which could be regarded as an attempt to avoid acknowledging the existence of the 'biomedical model'. We have already outlined the substantial contribution of psychiatry and the 'bio-psycho-social model' to public mental health in Table 2.4. Indeed, we reject any approach that does not fairly acknowledge the body of evidence accrued in psychiatric research, much of which features in the later chapters of this report. Furthermore, this 'rebadging' approach to psychiatry research evidence critically compromises the strength of the evidence base on which policy is subsequently built. As Stewart-Brown puts it: 'It is important that measures really do reflect well-being otherwise governments, commissioners of services and practitioners will be misled.'33

Another of the key drivers for the rebadging of psychiatric and other research as evidence that 'well-being works' may have its origins in an appetite to substantiate Foresight's hypothesis that 'improving the average level of well-being across the population would produce a large decrease in the percentage with mental disorder, and also in the percentage who have sub-clinical disorder (those "languishing")'. This hypothesis is widely cited within both well-being policy<sup>56</sup> and academic literature.<sup>23</sup> The original proponent of the theory is Huppert, originating from her collaboration with Rose. Huppert argues that the 'Rose' hypothesis can potentially be applied to population mental health. Rose<sup>57</sup> originally observed that in a population where a risk factor has a relatively normal distribution (e.g. blood pressure), the majority of illness arising from that risk factor (e.g. myocardial infarction) occurs in those who are located below the upper tail of the normal distribution, simply because there are so many more individuals located within that range. Rose's prevention paradox is that an intervention that benefits a large number of people at moderate risk may have a greater overall value than one that benefits a few people at high risk.

Huppert's first publication addressed this issue empirically, using GHQ data in a cross-sectional dataset.<sup>58</sup> In 1996 Whittington and Huppert extended this further, using follow-up data from the Health and Lifestyle Survey (where the GHQ-30 had been applied a second time, seven years later). They reported that a linear relationship existed between changes in the prevalence of psychiatric disorder (GHQ case-ness) and changes in the mean number of psychiatric symptoms in the population surveyed (captured by response to the GHQ-30).<sup>59</sup> In later writings emerging alongside the positive psychology movement,<sup>60</sup> Huppert followed this up

by drawing further direct parallels with the Rose hypothesis. She suggested that 'a very small shift in the population mean of the underlying symptoms or risk factors can do more to enhance well-being and reduce disorder than would any amount of intervention with individuals who need help'. 61 Huppert's interpretation appeared to be informed by an argument about the psychometrics of the relevant population distribution. Implicit was an assumption about the 'well end' of the GHQ continuum, not the end that is well understood (the morbidity range): it is questionable whether anyone has established that there is resilience or 'flourishing' at the top end of the GHQ range.

However, Huppert's use of the term 'well-being' in this paper seems to imply that she believes moving towards 'no symptoms' is synonymous with moving into a state of 'well-being'. It is impossible to be sure of this from the data available: do low GHQ scores identify a trait of 'resilience' (protective), or a desirable positive mental health state? The argument itself, on its own, does not establish this – it remains to be confirmed and should be tested. Huppert concedes that there is no empirical evidence that any interventions will have this effect, concluding 'what is needed now is to test whether interventions that produce small improvements in the population mean will lead to substantial improvements at both ends of the spectrum'. But from what we know about the GHQ-30 items, their measurement range extends across half of the desired (or implied) population distribution. The GHQ-30 items do not perform with equal measurement precision above the general population mean.

Since that argument and mathematical model was articulated, evidence for interventions that 'shift the curve' in public mental health has simply not been forthcoming. In light of this, and the above, we question how appropriate it is to continue propagating the case for well-being – defined by both Huppert and the Foresight Report as primary prevention of mental disorder – using Rose's approach in the absence of any empirical evidence. The psychometric evidence would require even further extension of the same continuum above the population mean. To date, this measurement range has never received full validation from this starting point.

Additionally, many of those working in the field of well-being and positive mental health would reject Huppert's definition of 'flourishing' theory on the grounds that they define wellbeing as more than the absence of disease. Adding further to the conceptual confusion around the subject, the word 'flourishing' is used entirely differently by Keyes to describe a state of well-being defined primarily by the attributes in Table 2.4 (which lists approaches to the subject rooted in the theory of positive psychology). Keyes and others argue that well-being – taken essentially to mean positive mental health – is a valid goal in its own right, including for those with a diagnosable chronic mental disorder. This is a concept with clear relevance to people with mental illness who are interested in the meaning of recovery.<sup>62</sup> In spite of brave attempts to review this complex territory, 63 there is a clear need for much more refined research first to define and psychometrically establish the concept of well-being as it

relates specifically to populations with mental illness before trying to develop an evidence base for well-being approaches to this group.<sup>64</sup>

Due to the relative newness of well-being as an academic field – coupled with the conceptual and measurement issues described above - the available evidence for effective and specifically defined well-being interventions in the field of public mental health is in its infancy compared with evidence from more established scientific disciplines. After the case for the promotion of mental health was made by the WHO in 2004/05, it was echoed by the Royal College of Psychiatrists in 2010.65 In their online web resource 'Better Mental Health for All', the Faculty of Public Health (FPH) set out their aims as 'the promotion of mental- well-being and the primary prevention of mental illness'.66 It does seem odd that the FPH do not explicitly aim for 'positive mental health' or 'mental health promotion', especially since the primary prevention of mental illness has proved thus far to be a vexed question. The FPH explicitly choose to define mental health differently from the WHO (whose definition is 'a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community') and instead conclude that their definition of mental health 'encompasses mental illness/disorder, mental well-being and all other states of mental health'. Having laid out its stall, the FPH resource attempts to link concepts of 'mental' and 'social' well-being in a theoretical framework. Problematically, this is then followed up with a series of unreferenced and suppositional statements, perhaps in an attempt to strengthen the case for the consideration of mental well-being as one of the two key outcomes that would achieve 'better mental health for all':

Mental wellbeing includes the capacity to make health and happiness enhancing relationships with others. People with mental wellbeing know themselves and their needs, have clear boundaries, relate to others using the skills of emotional literacy and accept and manage conflict without manipulation or coercion.

People with mental wellbeing are also generous, wise and compassionate. They make good decisions on behalf of others. It therefore follows that promoting the mental wellbeing of all, particularly of those who are in positions of power, is an important approach to preventing social inequality and unhealthy policy.

Mental and social wellbeing are thus closely interrelated but distinct concepts, which often appear muddled together in the literature.

FPH's concept of mental and social wellbeing addresses this bi-directional relationship, defining mental wellbeing as the attributes of the individual and social wellbeing as the attributes of 'others' collectively.

# Public mental health: evidence based priorities

We contend that in a field already bedevilled by a lack of definitional clarity, a unified approach towards definitions and terminology should be adopted among the key players in the UK. Unreferenced assertions overstating the case for well-being risk detracting from the credibility of the wider field. Table 2.1 outlines the consequences of a non-unified approach to the description of populations who experience positive mental health, which – adopting the approach suggested by the WHO – is the preferred terminology for this report.

# Well-being and public mental health: the quality of the evidence base

Much of the commonly cited evidence base for well-being intervention evaluations as related to mental health is located within the grey literature, i.e. papers and reports which have not been subjected to independent peer review and which are often published by the organisation that carried out the intervention.<sup>24</sup> A relatively small number of reports from the non-peer-reviewed literature do contain the results of large and generally high-quality research outputs carried out by respected methodology institutes such as NatCen Social Research and the ONS, whose approaches merit scientific exploration. What we refer to here, however, is the proliferation of commonly cited yet very poor-quality grey literature reports, articles and websites. While enjoying relative prominence, such anecdotal evidence nonetheless cannot hold its own against peer-reviewed scientific evidence in other closely allied social science fields. Other fields already largely self-govern within the space of the accepted hierarchy of evidence, many of which feature in later chapters of this report. This is a standard to which the field in question must surely aspire. Yet we continue to hear concerning pronouncements that grey literature should be considered to be of equal importance in the evidence base for well-being. On the basis of such evidence, this CMO has even been asked to take a 'leap of faith' regarding the case for well-being in mental health.

One of the most problematic implications of the use of grey literature is the widespread adoption of scientific-sounding statements from well funded but poor-quality studies which are based on flawed methodology. To explain our standpoint more comprehensively, we turn to a case study of a widely cited report covering aspects of well-being and mental health: Big Lottery Fund National Wellbeing Evaluation: Final Report (prepared by CLES Consulting and New Economics Foundation, 2013). This report offers 'lessons for service providers, commissioners, the Big Lottery Fund and Government', and its authors state 'we are confident that this evaluation is the most comprehensive evaluation of the impact of well-being interventions in the UK so far'.67 Indeed, we have observed conclusions from this report being cited at conferences and policy events. Of direct relevance to this chapter, the report claims that the well-being intervention being evaluated had a 'significant impact' on mental health. The executive summary of the report draws the following conclusion:

The programme as a whole was found to have significant impact on all three strands of well-being: mental health, physical activity and healthy eating as well as on participants' social well-being and personal well-being. The improvements to participants' well-being were found to continue beyond participation in the programme.

We were concerned that this report, like many others, may have overstated the case for the evidence base for well-being. We therefore commissioned an independent peer review of the report from three senior academics with expertise in the field. In doing so, we subjected the report to the level of scientific scrutiny it would have received had it been submitted to a journal for publication as health evidence – rather than being published by the organisation that commissioned or conducted the research. We provide the unanimously critical comments made by the peer reviewers in the case study at the end of this chapter. A summary of the peer review comments is provided below:

The conclusions presented in the report are not justified by the results presented in the document. The conclusions do not take any account of the significant methodological weakness of the design and analyses. If this report were submitted to a scientific journal they would require a substantial change in the level of detail given, further statistical analyses and to eliminate any statements that suggested the study could be related to any of the causal interpretations that are made. In sum, the conclusions presented in the report are presented as more definitive and reliable than they can possibly be.

The purpose of undertaking this exercise is to demonstrate the difficulties in drawing conclusions relating to well-being which are not based on the rigorous scientific standards that would be accepted in any other field which hopes to attract funding from public health bodies at both a national and local level. Innovative service developments in other areas of health research may often start with small, uncontrolled studies of new programmes led by enthusiastic people on somewhat selected participants. However, the limits of such research would be fully acknowledged and results would only be published from the subsequent fully controlled and peer-reviewed study. It is the latter type of evidence that should typically inform health policy. When conducted robustly, quantitative research evidence can be complemented by evidence from alternative methodologies in a field such as well-being. An example of this is qualitative research methodology, which has agreed standards for what constitutes scientific robustness.68 However, another particular frustration in the field of well-being evaluations is the frequent use of poor-quality qualitative evaluations that do not reach agreed standards for the field, further detracting from the credibility of the evidence base.

In challenging economic times, we contend that there is an even stronger imperative that public funds should be prioritised for investment in the many areas of public mental health for which we have robust evidence of effectiveness and cost-effectiveness. Well-being – a field in its infancy as related to mental health – forms a tiny part of an otherwise substantial public mental health evidence base. Furthermore, subjective well-being has a much longer, scientifically robust tradition within 'quality of life' research. In the health psychology literature, well-being is generally regarded as a pillar of quality of life. Thus many established measures of broader, health-related and disease-specific quality of life include domains measuring well-being. Strong correlations between these quality of life and life satisfaction (part of well-being) have been reported.<sup>69</sup> To the extent that wellbeing is a component of quality of life, and their measures overlap, the recent focus on the measurement of mental well-being in mental health outcomes might be regarded as reinventing the wheel, rather than building on this literature. This is especially the case as measures of quality of life have accrued a much more robust body of knowledge on their multi-dimensional properties and psychometrics. (For more details, see Appendix 1 to this report, 'The definition and measurement of well-being and quality of life in mental health promotion and outcomes'.)

Furthermore, we know that there is no evidence to suggest that well-being interventions reduce rates of mental disorder at a population level. If instead we take the WHO approach to public mental health (promotion, prevention and treatment/rehabilitation) and ignore all studies and reports that do not meet scientific standards (such as the report described above and in the case study at the end of this chapter), we are left with a field of well-being that is much diminished in size and relative importance to the concept of public mental health. Generic statements about 'improving well-being and mental health' should give way to a far more refined approach: at both a local and national level there are ample opportunities for mental illness prevention and treatment of and recovery from common mental disorder that we have the potential – and the evidence base – to address effectively. These are 'low hanging fruit' – we know what the problems are, what works and what saves money. Public health interventions that use a suitable approach and a robust evidence base have the potential to address a huge public health challenge, which is increasingly sidelined as the drive towards framing mental health in terms of well-being continues to ride ahead of the evidence.

#### Quality of review-level evidence for a 'wellbeing approach' to public mental health

In response to the high degree of policy interest, there has been a swathe of prominent 'reviews' and 'summaries' attempting to provide the evidence base to underpin a well-being approach to public mental health policy. It is concerning that non-robust grey literature, such as that described above, frequently finds its way into such 'review' or 'summary' evidence. Such products are themselves rarely independently peer reviewed and, at times taking a quasi-'review of reviews' approach, they are often characterised by one-sided promotion of any summary literature that appears to support the concept, whether it be peer reviewed or not. 51,70,71 They do not adhere to the standards prescribed by the PRISMA Statement reporting guidelines or the Cochrane Collaboration. 73

Such reviews should not be used as justification for the effectiveness or cost-effectiveness of taking a well-being approach to public mental health. Robust reviews are unbiased and transparent. They use specific research questions, systematic search strategies, strict inclusion criteria. weighted analysis of included studies according to the hierarchy of evidence, a meta-analysis (or at the very least an attempt to quantify effect sizes) and a frank discussion of any inherent biases in the review. We agree with those working in the field that there may be instances in which a quantitative systematic review may not be the most appropriate review methodology for this type of evidence, but any alternative approach should instead follow academically accepted robust principles – as echoed by the WHO and summarised in Table 2.2. Examples of alternative review methodologies with scientific consensus statements include meta-narrative reviews and realist syntheses which adhere to the RAMESES publication standards published by Wong et al. 74,75 In the absence of high-quality reviews, it is difficult to hold to account resource allocation for well-being approaches to public mental health based on poor-quality review research.

The methodological problems inherent in policy-relevant evidence summaries undermine the credibility of the wellbeing field and indeed detract from some of the high-quality review-level evidence that the field has to offer. We are particularly encouraged by the publication of rather more robust review-level evidence for well-being approaches to promoting mental health and preventing mental illness in children and young people, many of which have been incorporated into helpful and practical NICE guidelines.<sup>76–78</sup> Indeed, informed by the evidence base, the importance of this was a key message of the CMO's annual report 2012.79 There is some evidence to support an approach to mental health promotion in the elderly that uses occupational therapy and physical activity interventions; this may improve 'well-being', but unresolved definitional and measurement issues are once again apparent in the background work upon which the guidance is built.80 Indeed, there appears to be relatively little high-quality review-level evidence to support the improvement of adequately defined and measured 'well-being' in the adult population. A notable exception is

# Public mental health: evidence based priorities

the background review to the NICE guideline on promoting mental well-being at work. This review<sup>81</sup> is transparent and frank about the definitional and methodological difficulties posed by the review question itself, and reaches a measured set of conclusions that sit behind a rather 'black and white' guideline. Indeed, it is striking to note that most of the sufficiently robust reviews relating in some way to well-being and public mental health have caveated their findings by explicitly noting the poor quality of the evidence base, the heterogeneity of included studies, the lack of validated measures and the over-reliance on measures of disorder.<sup>82</sup>

#### What works in well-being and mental health?

As discussed above, we currently have no consensus about what well-being actually is when considered in terms of mental health and mental ill health – let alone how to measure it and how we might develop, implement and evaluate interventions to improve it. In spite of this, there continues to be published a stream of reports, documents and evaluations claiming to provide evidence of 'what works'. This approach is fuelled by the promotion of very poorquality toolkits and well-being promotion guides aimed at local government, which base their work on the scientifically flawed premises that we have laid out in this chapter. The result is that such publications encourage well-being interventions to be developed and evaluated prematurely.83,84 We recommend that, if well-being interventions are to be innovated in the field of public mental health at both a local and national level, they should be carried out in full acknowledgement of the problems inherent in the field, using the Medical Research Council (MRC) Complex Interventions Framework<sup>85</sup> to ensure that a robust yet practical approach is taken to investment in this area. This will also allow innovation by local government to take into account the local public health needs of populations, including social and health inequalities and ethnic diversity. For those working in government, another useful resource to inform robust assessment of the quality of well-being interventions is The Magenta Book, published by HM Treasury in 2011.86

# Public mental health and wellbeing: a way forward

As we draw the content and conclusions of this chapter together, it becomes apparent that there is a pressing need for this report to make the case for reconceptualising public mental health in England. Well-being policy is running ahead of the evidence. In framing public mental health in terms of 'well-being', by developing 'well-being' frameworks and policies which are over-reliant on poor-quality evaluations and reports of 'well-being' interventions in mental health, we detract from the credibility of the field and fail to lead by maximising the potential for policy based on the excellent evidence for effective public mental health that we already have. We have reviewed prominent reports and documents which collectively encourage local government investment in a well-being approach to the mental health of populations.

We have provided evidence in this chapter that this is not an appropriate use of funds at this time. We bring clarity to this issue by summarising our key messages for commissioning in Box 2.4.

Well-being in mental health could have much to contribute to the debate. However, high-quality research is needed first, which aims to answer the fundamental definitional and metrics questions we outline in this chapter, particularly with regard to the psychometric properties of various measurement scales and their applicability to the sub-populations that comprise 'public mental health'. We contend that until this work takes place and we have reproducible, reliable evidence, the majority of claims to provide 'evidence that well-being works' are unfortunately beside the point.

We recommend instead using the WHO approach to public mental health to redraw the boundaries of public mental health as outlined in Figure 2.2. Using this framework, it becomes easy to identify where we have high-quality evidence and how each piece of evidence relates to the broader concept of public mental health and the component, interrelated parts of mental health promotion, mental illness prevention and treatment and rehabilitation. We demonstrate this by providing specific examples of such evidence in Figure 2.2. The Rose hypothesis has not been fully worked through for populations and mental illness, and the intersection between 'mental health promotion' and 'mental illness prevention' in Figure 2.2 is where the evidence base requires strengthening in order to progress that agenda.

We strongly recommend that local authorities, the NHS and clinical commissioning groups structure their funding and interventions in mental health using our framework. We strongly discourage commissioning from 'mental wellbeing' into clinical care pathways. We call on the Medical Royal Colleges and the Faculty of Public Health to unite behind a common definition and understanding of public mental health for the benefit of the populations they care for. We also call on central government departments, Public Health England, NHS England and others to adopt the WHO approach and consider well-being to be one strand of the overall picture, rather than a scientifically problematic concept that is embedded into all work and that receives priority funding over better established fields, including quality of life.

# Public mental health - a conceptual model derived from the WHO framework (illustrated with examples from the peer reviewed evidence base)

(illustrated with examples from the peer I Copeland et al. Adult psychiatric outcomes of bullying and being bullied by peers in childhood

Vreeman et al. A systematic review of schoolbased interventions to prevent bullying. Arch Pediatr Adolesc Med. 2007 Mindfulness-based cognitive therapy (MBCT) was developed with a specific focus on preventing relapse/ recurrence of depression (Segal et al., 2002). With 8 to 15 patients per group, MBCT has the potential to help a large number of people. (NICE CG90 – Depression in Adults: Full Guidance)

Wolchik et al. Six-year follow-up of preventive interventions for children of divorce: a randomized controlled trial. JAMA. 2002

Svensson et al. **Schizophrenia susceptibility and age of diagnosis-a frailty approach.** Schizophr Res. 2013

Kessler et al. Associations of housing mobility interventions for children in high-poverty neighborhoods with subsequent mental disorders during adolescence. JAMA 2014 Interventions to encourage moving out of high-poverty neighbourhoods were associated with increased rates of depression, PTSD, and conduct disorder among boys and reduced rates of depression and conduct disorder among girls. Better understanding of interactions among individual, family and neighbourhood risk factors is needed to guide future public housing policy changes.

Treatment, recovery and ehabilitation

Tennant et al. A systematic review of reviews of interventions to promote mental health and prevent mental health problems in children and young people. Journal of Public Mental Health.

mental health of the offspring: Systematic review and metaanalysis. J Am Acad Child Adolesc

Psychiatry, 2012

mentally ill parents on the

and adolescence. JAMA Psychiatry. 2013

schools adopt a comprehensive, 'whole school'

approach to children's social and emotional

and agree arrangements to ensure all primary

children in primary education should develop

Commissioners and providers of services to

wellbeing (NICE PH12 Social and Emotional Wellbeing in Primary Education)

Egan et al. The psychosocial and health effects of workplace reorganisation. A systematic review of organisational-level interventions that aim to increase employee control. J Epidemiol Community Health, 2007

Cattan et al. Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions.
Ageing and Society. 2008

promotion

prevention\*

Mental Illness

Mental health Ageing and society. 2008

Schrank et al. Determinants, self-management strategies and interventions for hope in people with mental disorders: systematic search and narrative review. Social Science and Medicine. 2012

Low intensity psychological interventions for Generalised Anxiety Disorder, offer one or more of the following as a first-line intervention, guided by the person's preference: individual non-facilitated self-help; individual guided self-help; individual guided self-help; proceeducational groups. (NICE CG113 - Generalised anxiety disorder and panic disorder (with or without agoraphobia) in adults: management in primary, secondary and community care).

Davies and Mehta

\* Primary, secondary, tertiary or universal, indicated, selected prevention

Annual Report of the Chief Medical Officer 2013, Public Mental Health Priorities: Investing in the Evidence

# Box 2.4 Commissioning in mental health: key messages for policy

- Public mental health should be framed according to the WHO model of mental health promotion, mental illness prevention and treatment and rehabilitation. There is a robust evidence base for the WHO model, drawn from diverse academic disciplines that study population mental health. This approach should be embedded across the work of local and central government.
- 'Well-being interventions' and services should not be funded in public mental health, but considered as one (poorly evidenced) strand within the WHO model of public mental health: mental health promotion, mental illness prevention, and treatment & rehabilitation. The promotion of mental well-being at a local level has insufficient evidence to support a co-ordinated priority approach using universal or targeted well-being interventions. There is no evidence that well-being programmes can reduce the burden of mental illness at a population level using the Rose hypothesis. Well-being interventions should not be funded using this as the rationale.
- 'Well-being' has not yet been scientifically defined and measured in an acceptably robust way. Therefore well-being measures (as they currently exist) should not be used to allocate and evaluate health resources.
- Subjective measures relating to mental health from the ONS Measuring National Well-being Programme are designed as population measures, and some of them measure disorder, not well-being. Furthermore, it is possible that one of the 'non-disorder' measures the WEMWBS may, at the lower end of the scale, also be measuring populations with clinical disorder. Further national work is required to clarify the psychometric relationships between measures of well-being and measures of mental disorder/illness. Until a sufficiently robust set of indicators for use at a population level are developed, local government bodies cannot be held to account for 'improving well-being'.
- The NHS, Public Health England and Clinical Commissioning Groups should not commission services that 'support mental well-being', but should instead focus on investing where there is an evidence base. This falls clearly within the spheres of treatment and rehabilitation, mental illness prevention and mental health promotion. It is consistent with a public health model that integrates population approaches towards physical and mental health.
- Well-being social marketing campaigns for public mental health should not be rolled out until there is robust evidence for their effectiveness. There is currently no good evidence.

# **Conclusion**

To summarise, we have used this annual report to provide a framing discussion for public mental health and well-being. We hope that this will be helpful to all those working in the fields of public mental health and psychiatry, whether at a national or local level, in positions of leadership or at the front line.

We attempt to bring some clarity to the terminology used within the field of public mental health, noting that there is no universally acceptable lexicon to describe the experience of people with mental health problems but arguing for a consistent approach in order to avoid unhelpful euphemisms, to define boundaries and to minimise the potential for confusion when striving to achieve parity of esteem, funding and outcomes.

We summarise the WHO's approach to public mental health, which has been incrementally built over the last decade and which culminated in the 2013 WHO Mental Health Action Plan. The WHO helpfully considers public mental health as a triad of mental health promotion, mental illness prevention and treatment and rehabilitation, and has set out a compelling case for viewing the topic in this way.

Moving on to a discussion of public mental health in England, we note that the Foresight Report (2008) started a debate which hypothesised that a well-being approach to mental health could 'shift the curve', i.e. that it might give us an evidence base for the primary prevention of mental illness. It was a tempting prospect, and national and local government enthusiastically embraced well-being policies. Over time, and with the emergence of locally led public health, there has been an increasing drive for local government, health and well-being boards and public health and other professionals to use 'well-being' as a prominent framing tool for public mental health, and to embed well-being in all aspects of policy and practice. At the same time, the ONS embarked on the challenge of measuring 'national wellbeing'.

Concerns have emerged over the past few years that wellbeing is difficult to define, difficult to measure and therefore difficult to integrate in any meaningful way into public mental health. The ONS approach to measuring national well-being – in so far as it is relevant for mental health – is one of the more robust attempts to unpack the problems that we have uncovered, and we discuss this approach in some detail. What is striking, however, is the narratives that arise alongside studies using measures that were developed in the context of epidemiological or screening studies for mental disorder as well-being indicators, such as the GHQ and single-item or short-item sets (e.g. the ONS's 'anxiety vesterday'. We take a detailed look at whether this approach is psychometrically valid and conclude that it is a very complex field and that those promoting a well-being approach to mental health simply must engage with new combinations of items. Our thoughts on this, in consultation with experts, are that the psychometrics as we currently understand them

do not appear to stack up. We further comment that an approach to well-being that uses item sets whose properties are only robustly validated in the context of identifying groups with increased risk of minor psychiatric disorder risks further complicating the boundaries and definitions that we sought to clarify early in this chapter.

This brings us to a discussion of definitions and metrics of well-being within public mental health – perhaps the key plank of understanding that we seek reproducible and robust evidence on. We note that much of the 'well-being' literature in mental health inappropriately describes the results of intervention studies and trials in more established disciplines into the prevention and treatment of mental illness as part of a 'well-being' evidence base to which they cannot scientifically be said to apply. This results in 'proxy' outcomes being unscientifically rebadged as 'well-being' outcomes and critically compromises the strength of the evidence base upon which policy is subsequently built.

We examine the hypothesis of the Foresight Report – namely that well-being interventions in mental health can 'shift the curve' and 'reduce the percentage of those with mental disorder' – and find that this does not hold true as disorder and well-being do not exist on a continuum. We note that, in any case, the approach used by Foresight is not supported by much of the well-being community because the paper upon which the theory is based suggests that the definition of 'flourishing' is the absence of symptoms of illness. This leads us to a review of statements of understanding of well-being and mental health, and we note that the approach of the FPH differs fundamentally from that of the WHO. We suggest that it would be preferable to take the lead from the WHO to help bring some clarity to a very unclear field.

Having explored the definitional and measurement issues inherent in a well-being approach to mental health, we turn to a discussion of the quality of the evidence base. We note our concern that much of the commonly cited literature for well-being in mental health is located in the non-peer-reviewed grey literature (including magazines). The findings of such studies are often very misleading and this quality of evidence simply would not be accepted as a basis for policy making in any other branch of health – and should not be here. We give a case example of a large, well funded but non-peer-reviewed evaluation of a series of well-being interventions that claim to offer lessons to service providers, commissioners and government, among others. We provide the results of an independent peer review that we commissioned, and note with concern that the unanimous comments of all three peer reviewers suggest the strong conclusions presented in the paper about well-being interventions improving mental health are, in fact, misleading and scientifically invalid.

We point out that there is already a high-quality evidence base incorporating validated measures of well-being within quality of life research. Professor Ann Bowling has contributed an excellent appendix to this report (Appendix 1, 'The definition and measurement of well-being and quality of life in mental health promotion and outcomes') in which she points out that much of the work attempting to understand well-being may, in fact, be reinventing the wheel as the definition, psychometric properties and measurement of well-being have already been considered in detail within broader quality of life research about mental health promotion and mental health outcomes.

We move on to a discussion about the quality of review-level evidence and note the existence of apparently well regarded 'well-being evidence reviews' that do not use commonly accepted methods for the production of unbiased and transparent reviews (such as those laid out by the PRISMA Statement and the Cochrane Collaboration). We welcome the existence of a handful of higher-quality reviews, some of which have resulted in NICE guidelines specifically about well-being. However, we do note that the better-quality reviews in the field have all highlighted the definitional and measurement issues that we have discussed here in detail. as well as commenting on the poor quality of the available primary sources of evidence. We therefore encourage NICE to reflect appropriately these uncertainties in the guidelines that they produce, to ensure that all NICE outputs in the field of well-being meet the high standards we expect.

We briefly discuss the usefulness of current approaches to finding out 'what works' in well-being and mental health. Noting the widespread use of poor-quality toolkits and guides aimed at local government, we suggest instead that local innovation in well-being for mental health should follow the principles laid out by the MRC Complex Interventions Framework or, for those in government, The Magenta Book, produced by HM Treasury in 2011.

We finish by offering a useful framework for well-being work in mental health. Drawing on the WHO approach to the subject, we consider public mental health as consisting of three overlapping domains: mental health promotion, mental illness prevention and treatment and rehabilitation. In Figure 2.2 we provide specific examples of the ways in which different types of evidence from different disciplines and fields fit into this model, and suggest that this is a far more robust framework for all those working in the field of public mental health to adopt. We know that the evidence for wellbeing in mental health is largely restricted to a small number of specific interventions to improve the well-being of children and young people, and we use Figure 2.2 to demonstrate the main examples we have of scientifically acceptable evidence which can and should be used to inform local and national public mental health improvement using a wellbeing approach. We also include other high-quality research. which should not be subsumed in an ad hoc fashion under a 'well-being' banner but should be acknowledged for what it is within the rubric we outline, and prioritised for funding in the same way. This will avoid the problem of inconsistent rebadging of other evidence as 'well-being' and prevent the term from obscuring a logical, systematic and evidence based approach to improving the mental health of populations.

# Public mental health: evidence based priorities

There is no place within our model for poor-quality evidence. We do not call for a reduction in funding for mental health at a local level, but we do contend that there is enough good-quality evidence to make a real and sustained public health impact on the mental health of populations by more effectively deploying what we already know. We call on Public Health England, the FPH, the Royal College of Psychiatrists, the Local Government Association and directors of public health to follow the lead of the WHO and disseminate the evidence that already exists in public mental health in a clear and scientific manner. Finally, we encourage all those working in the field of well-being as it relates to public mental health to agree on common definitions and suitable metrics, and to develop and evaluate suitable interventions to a high standard. Once this work gathers pace, we encourage them to support public mental health with their own evidence – innovating and disseminating on the same terms and using the same standards as achieved by the other disciplines whose work is cited within this framework.

Box 2.5 Case Study – peer review of 'Big Lottery Fund National Well-being Evaluation – final report prepared by CLES Consulting and the New Economics Foundation' (August 2013)

#### **Overview**

This report does not contain enough information about the methods used. The result is that there is insufficient quality of evidence to assess whether interventions aimed at improving health, mental health, social inclusion or physical activity (broadly, loosely and poorly defined in the report under a banner of 'well-being') will have any public health benefit. There is insufficient evidence from this report to favour (or not) well-being initiatives in the general population.

#### **Definitions of well-being**

The report does not define what it means by well-being. The report does not provide empirical psychometric evidence (published in peer reviewed scientific journals) to support well-being as a latent construct underpinned by the three domains of health (mental health, physical health and healthy eating) that are stated as the focus of the report. It is unclear whether well-being is taken as a distinct concept or as the opposite end of a continuous scale to ill (mental or physical) health. Despite stating that the report will focus on three strands (mental health, physical health and healthy eating), it goes on to report additional findings on 'personal wellbeing' and 'social wellbeing'. Social well-being is poorly defined in the report, which focuses on four 'subdomains' of social well-being. The theoretical or empirical value of these domains is absent, and furthermore the report then only presents results (Figure 4) based on three single items. Single items rarely provide sufficient information to capture a larger construct but in addition there is no rationale here for why these items alone were reported or how they purportedly map onto the four subdomains of social well-being.

#### **Definitions of mental illness**

The report states that it uses a revised version of the CES-D to assess depressive symptoms. This appears in a footnote as a 7-item scale. However details of the version are not given. The number of items reported in the version used by the report differs from accepted and published versions of the CES-D (including the CESD-Revised or the short form CES-D-10) raising the possibility that the CES-D version used in the report is not a valid measure of overall levels of depression. Furthermore, the validity and rationale for using a cut off score of 12 to indicate clinical depressive disorder in this report are not given, raising further doubt as to

the validity of the construct. As the report states 'no strict guidelines exist for our set of questions...'; this is because the version of the CES-D used has not been validated. The report also includes results on two further aspects of mental health ('stress' and 'anxiety'), but no detail of the assessments used to evaluate these constructs is given in the report.

#### Study design

The study appears to involve a comparison between before and after engagement with one of the 17 Well Being programme and Changing Spaces programmes funded by the Big Lottery. There is limited detail on the research participants – this makes it difficult to determine who the results might apply to. For example, how many of the participants have clinically significant mental illness? We would need to know this if we wanted to determine if this sort of programme helped such people – and to interpret the report's finding that mental health and well-being are strongly linked. The report mentions a random stratified sampling strategy but there are no further details on how this was done. The report mentions that 5805 questionnaires were sent out but does not specify the non-response rate for this part of the survey. There were then 1964 (34%) returns on leaving the programmes and 572 (9.8%) for the follow-up.

The study design appears to have been of multiple small (n=20-50) uncontrolled projects – with the results then being pooled (method unspecified) for the final report.

A significant limitation of this design is that there was no comparison group. The design should have randomised participants between the intervention (here the well-being programmes) and some alternative (which in this instance could have been to continue with usual activities). Without randomisation there is the possibility that the intervention is being evaluated in a non-comparable group. Without a comparison group it is impossible to conclude that the intervention has had any effect on well-being. It is possible, for example, that the participants in these programmes will have chosen to participate because they wanted to change various aspects of their lifestyle. Without a comparison group it is impossible to conclude that the well-being programmes were influencing changes that might have occurred in any case.

The non-response at the end of the programme and at follow up are likely to introduce additional bias. It is likely that the people who stayed in the programme and those that completed the follow up questionnaires thought that they were benefiting. The other 60% of participants might have dropped out because they were feeling worse or because they did not find the programme helpful. Of note is the evidence that people with poor mental health are more likely not to

respond to surveys – so this effect on its own would lead to an 'improvement' in scores similar to those that they report. The report could have addressed some of these possibilities by carrying out further analyses to investigate the likely impact of this missing data (multiple imputation). However, given the lack of comparison group this would not be worthwhile. The bias could be very extreme for the 10% who provided results at the follow up assessment. The 'loss to follow-up' figures are even more problematic for specific domains of well-being considered in the report. For example, with respect to depression, only 1060 completed the exit survey (32.4% of the original sample), while only 24 (0.7%) and 23 (0.7%) participants completed the stress and anxiety assessments at follow-up. This renders meaningful interpretation of results relating to these groups impossible.

#### Statistical methods

Analysis and significance reporting

There are insufficient details about the approach taken towards analysis. For example, were people only included who had data on both baseline and follow-up? There is an overemphasis on interpreting p values and no confidence intervals. The confidence intervals reported in the appendix are irrelevant, since confidence intervals refer to specific analyses and depend on the sample size in each of the said analyses.

#### Confounding factors

All associations presented in the report are univariate without control for confounding factors. Thus, a change in well-being item from baseline to exit to follow-up may be attributable to unobserved confounding factors (including changes in employment over the study period, ageing, life events, changing social circumstances, the weather, GDP, national events of importance and so forth). Any number of unobserved confounders may explain differences over time, but no multivariable regression techniques have been used to control for the effect of potential confounders. This problem permeates all of the results in the report, including those related to mental health.

#### Stratification by age

There is no clear rationale for why the results for children of secondary school age have been grouped with adults over the entire set of outcomes considered.

Correlation and pathways through which different wellbeing outcomes are related

The report presents the correlational structure of four domains in Figure 14 (mental health, personal wellbeing, healthy eating, physical activity). The following scientific problems exist with this:

- 1. Personal well-being is inextricably placed at the centre of the diagram and shaded in a different colour to the other domains, as if to imply that it is somehow underpinned by the other three domains. Since these are correlations this is an entirely arbitrary decision without theoretical or empirical justification.
- 2. It is unclear whether the correlation is based on outcomes as assessed at baseline, exit or follow up.
- 3. It is unclear how the summary measures for each domain have been calculated.
- 4. The largest correlation is between mental health and personal well-being. Since these constructs are not empirically established as distinct latent constructs, this does not imply that improvement in one domain (i.e. mental health) would lead to improvement in another (i.e. personal well-being). Rather the items which are used to measure mental health are probably closely related to the items used to measure personal well-being, and the two 'constructs' actually may be tapping into the same broad area of health.
- 5. The 'pathways' through which one domain of health leads to another domain of health are all provided from qualitative research studies. While such data might be valid, it should be noted that no attempt to test pathways in the empirical data has been attempted (i.e. structural equation modelling would allow one to test direct effects of one construct on others and test hypothesised pathways).

Section 4.1.1 through to Section 4.1.5 make frequent references to evidence from the quantitative data that one domain of health (i.e. healthy eating) resulted in improvements in another domain (i.e. mental health) – see Section 4.1.2. No quantitative data of this sort is presented in the report and as such these conclusions are invalid.

Figures 15 and 16 seem appealing but at best present theoretical ideas for how self-confidence and positive cycles of well-being might be relevant to the report. They present no evidence from the empirical data (as presented) and would likely be removed in any peer reviewed publication.

#### **Summary**

The report's Executive Summary concludes: 'The programme as a whole was found to have significant impact on all three strands of well-being: mental health, physical activity and healthy eating as well as on participants' social well-being and personal well-being. The improvements to participants' well-being were found to continue beyond participation in the programme.' This conclusion is not justified by the results presented in the document. The conclusions do not take any account of the methodological weakness of the design and analyses. If this report were submitted

# **Chapter 2**

to a scientific journal they would require a substantial change in the level of detail, further statistical analyses and to eliminate any statements that suggested the study could be related to any of the causal interpretations that are made. In sum, the conclusions presented in the report are presented as more definitive and reliable than they can possibly be.

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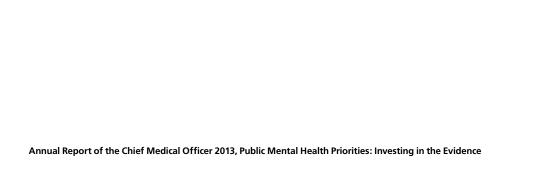
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Section 2 Science and technology



# Chapter 3

# Neuroscience and mental illness

# **Chapter authors**

Carmine M Pariante<sup>1</sup>, Akshay Nair<sup>2</sup>

- 1 Professor of Biological Psychiatry and Head of the Stress, Psychiatry and Immunology Laboratory and of the Section of Perinatal Psychiatry, Institute of Psychiatry
- 2 NIHR Academic Clinical Fellow, Department of Old Age Psychiatry, Institute of Psychiatry

#### Overview

In this chapter we discuss recent advances in our understanding of the biology of mental illness. Alongside important social and psychological factors, the biology of psychiatric disorders plays an important role in their development and prognosis. The inclusion of this chapter in this report reflects the need to widen public awareness of the quality and breadth of scientific work currently under way to help those suffering from mental illness. There is a stark mismatch between the funding for such research and the considerable cost of these disorders to our society, exacerbated by the recent disengagement of many pharmaceutical companies from research related to brain disorders. Translating the promising findings presented here into improved clinical care requires this mismatch to be addressed urgently. One way of doing this is by building bridges between the diverse fields involved in the common pursuit of the promotion of public mental health, which is one of the aims of this chapter.

It would be impossible to summarise the entire field of biological psychiatry for such a chapter. Instead, we have adopted a 'horizon-scanning' approach to demonstrate the variety of techniques used in this area, and to highlight a few examples that are more likely to have a rapid impact on patients' care. The chapter is divided, by technique, into sections covering neuroimaging, neuropsychology, genetics, blood-based biomarkers and animal and cellular models of disease. Some of the work presented here is already available clinically, such as the genetic analysis in autism. Other work could have widespread clinical utility within the next 10 years, especially in the area of 'personalised' treatment identifying a priori the best treatment for the individual patient. However, translating this neuroscience research into better patient care requires sustained support of experimental medicine and clinical trials.

It is our hope that this chapter demonstrates how biological research may aid diagnosis, risk stratification and the development of novel medications for the treatment of mental illnesses. Rather than distancing psychiatry from important psychological and social factors, much of modern biological research is aimed at understanding how these factors interact to produce disease states. Biological advances are likely to play a valuable part in the holistic management of patients.

We write this chapter to advocate that the biomedical and psychosocial models of mental illness are not antithetical, but are in fact increasingly conceptualised within a single unifying framework. While most of the important factors determining the risk and course of mental illnesses can be measured in a clinical interview, rather than in a laboratory, neuroscience research offers the exciting opportunity to understand the **mechanisms** by which these factors affect their clinical action. Unfortunately, at a public health level it appears that, while a biological model of mental illness enhances the

acceptance of treatment, it does not seem to be associated with a reduction in stigma among the general population.

Our understanding of the biological correlates of mental health and illness is growing exponentially. As showcased in this chapter, we are beginning to see how this understanding could be developed to improve the medical care patients with mental illness receive, and to widen our understanding of mental illness as a truly bio-psycho-social construct.

# Introduction

Many mental disorders are both chronic and disabling. It is estimated that they account for 14% of the global disease burden.<sup>1</sup> In 2011 the Department of Health estimated that mental health represented 23% of the UK national disease burden and was the single largest cause of disability.<sup>2</sup> The Centre for Mental Health found that in 2009/10 the total economic cost of mental illness in the UK was £105 billion, and it is estimated that treatment costs will double in the next 20 years.<sup>2,3</sup>

Despite the enormous health and economic burden that mental illness places on society, the funding for mental health research remains relatively limited. The Academy of Medical Sciences (2013)⁴ found that mental health research spending was only 5.5% of total UK health research spending in 2009/10. This is significantly less than the proportion spent on cancer, infection, neurological disease or cardiovascular disease. The European College of Neuropsychopharmacology (ECNP)⁵ highlights that, across the EU, neuroscience research receives just €465 million out of a total health research spend of €6,050 million – that is, less than 8%.

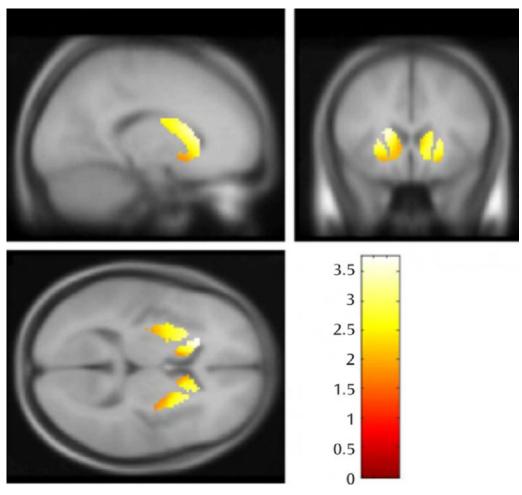
It is also interesting to note that both the report from the Academy of Medical Sciences (2013)<sup>4</sup> and the report from the ECNP<sup>5</sup> cite the recent withdrawal of pharmaceutical companies from brain research as a source of major concern.

This withdrawal is due, at least in part, to the challenge of translating research findings into clinical practice in psychiatry and psychopharmacology. For example, it takes on average 13 years to develop a drug for psychiatric conditions, significantly longer than for other medical specialities, and these drugs are also more likely to fail in the development process. There is an urgent need to overcome these obstacles and to plug this 'translational gap'. In this chapter we will highlight research that aims to do just that, while emphasising that the translation of neuroscience research into better patient care requires sustained support of experimental medicine and clinical studies.

Cutting-edge methodology in neuroscience is being used to study psychiatric disorders, and findings from these studies may have the potential to change clinical practice and improve patient care. This chapter showcases a selection of established techniques. It is organised by methodology and highlights some of the advances in neuroimaging, neuropsychology, blood-based biomarkers, genetics and cellular neuroscience, all as applied to mental illness. Some of the work presented here is already available clinically, such as the genetic analysis in autism, whereas other work could have widespread clinical utility within the next 10 years, especially in the area of 'personalised' treatment – identifying a priori the best treatment for the individual patient.

Before we discuss the individual research areas, it is important to highlight that this chapter does not aim to present

Figure 3.1 PET imaging of dopamine synthesis in psychosis (from Howes et al 2011)



neuroscience research as antithetic to the psychosocial model of mental illness. Indeed, some of the most exciting research in this area is specifically focused on the understanding of how psychosocial factors affect brain mechanisms. Therefore, this chapter advocates a unified bio-psycho-social model, where clinical factors assessed in an interview and biological factors assessed in the laboratory can both contribute to the understanding of the individual patient's journey, and improve patient care by providing new treatment approaches or new personalised approaches to existing treatments.

Finally, it is important to emphasise that the 'biological model' has brought both success and disappointment to the wider framework of social acceptance of mental illnesses. For example, while the wider understanding of the biology of mental illness seems to bring about better acceptability of professional help, it does not increase social acceptability, perhaps because it may increase a perception of 'otherness'.6 Our position, therefore, is that neuroscience research should contribute to a balanced, integrated, bio-psycho-social model of these conditions.

#### **Neuroimaging**

Brain scans have played a role in psychiatry since the 1970s.<sup>7</sup> Using advanced neuroimaging techniques, researchers are able not only to see the structure of the brain in unprecedented detail but also to measure dynamic properties such as blood flow, metabolism, electrical activity and neurochemistry. The ability to combine both structural and 'functional' data is vital to understanding the nature of the complex relationship between brain abnormalities and mental illness.

While many studies over the years have used neuroimaging techniques to compare patients and controls in a cross-sectional manner, the most recent developments have focused on the use of neuroimaging as a tool to predict the **future** course of disorders.

For example, particular interest has been shown in the application of neuroimaging to detect patients at high risk of developing psychotic disorders.8 Characterised by symptoms such as hallucinations, delusions and disordered thinking, psychotic disorders like schizophrenia are among the most disabling illnesses. Prior to the onset of illness it appears that patients display prodromal clinical features referred to as the 'at risk mental state'. 9,10 Subjects may not experience sufficient symptoms to warrant a diagnosis of a psychotic illness, but show warning signs. Approximately one-third of these patients go on to develop psychotic illnesses.<sup>11</sup> Reliably predicting this transition would allow patients to access treatment and support earlier, thus promoting recovery, reducing the need for emergency management and minimising the impact of illness on the patient's life. It is important to emphasise that these phenomena are not rare: for example, within the general population (where most people do not seek help from mental health services), 8–13% experience psychotic symptoms such as hallucinations or delusional ideas, with some experiencing both.<sup>12</sup>

Recent work shows that neuroimaging may be able to inform the risk stratification of these patients in the near future. Subtle changes in brain structure uncovered through magnetic resonance imaging (MRI), such as changes to the brain's grey matter volume, are detectable in patients before they develop psychotic illnesses and predictive of the change in clinical state.<sup>13,14</sup> Positron emission tomography (PET) has also shown that the capacity to synthesise the neurotransmitter dopamine in certain regions of the brain is elevated before the onset of psychosis in these 'at risk' patients. 15,16 Combining imaging modalities or adding other forms of data, such as genetic information, may improve the accuracy of these predictions and inform the clinical risk assessment.<sup>17,18</sup> Moreover, computational techniques like machine learning can also be used to evaluate MRI data and quantify the risk of transition to psychosis, as well as the individual course of illness in patients who have developed psychosis.19,20

Neuroimaging has also been used to investigate why some patients do not respond to treatments such as medication. Detailed structural imaging of gyrification (brain folding) and of white matter tracts has demonstrated baseline differences between patients with first episode psychosis who later respond to antipsychotic medications and those who do not.<sup>21,22</sup> PET imaging has found that a reduction in dopamine release predicts a lack of response to treatment and a worse clinical outcome in patients with cocaine and methamphetamine addiction.<sup>23,24</sup> A number of investigators have used neuroimaging to predict response to antidepressant treatment in patients with depression. The most consistent finding is that increased baseline activity in an area of the brain known as the 'anterior cingulate cortex' is predictive of a higher likelihood of positive response.<sup>25</sup> This evidence has also prompted the recent development of deep brain stimulation of the anterior cingulate area as a therapeutic strategy for patients with treatment-resistant major depression.26

One of the most exciting developments in neuroimaging is the analysis of the networks within the brain known as the 'connectome'. Using techniques such as diffusion tensor imaging (DTI) and functional MRI (f-MRI), it is now possible to map and measure connections within the brain.<sup>27</sup> It is believed that the many complex functions of the brain emerge from the co-ordinated activity of a number of regions, connected as specialised networks. Brain dysfunction can therefore be considered in terms of altered neural connectivity. A number of studies of schizophrenia have found evidence of altered connectivity between multiple brain regions, 28-30 including some highly specialised interconnected brain networks.31 Bleuler, who coined the term 'schizophrenia' in 1911, believed that a central pathological process in this disease was the interruption of the 'thousands of associative threads which guide our thinking'.32 Using modern imaging of brain networks, we may be closer to understanding whether there are robust and relevant biological underpinnings to his original clinical observations.

Finally, neuroimaging is contributing to our understanding of the impact of psychosocial factors on brain function. For example, recent research has shown that patients at their first episode of psychosis show a smaller volume of the brain structure known as the 'hippocampus' if they experienced traumatic experiences in their childhood, and that this effect is due to an increase in peripheral blood hormones related to stress (see also 'Blood-based biomarkers').<sup>12</sup>

#### Neuropsychology

The cognitive theory of depression highlights the importance of thinking errors in this condition.<sup>33</sup> A person suffering from depression is more likely to interpret a neutral stimulus as being negative, and focus on (and remember) negative stimuli more than positive ones.<sup>34</sup> For example, when recognising emotional facial expressions patients with depression are more likely to demonstrate a reduced perception of happy facial expressions and an increased perception of negative facial expressions.<sup>35–37</sup> These 'negative biases in information processing' are believed to feed a cycle that results in worsening mood, and helping to correct them is a fundamental part of cognitive behavioural therapy (CBT) for depression, a form of talking therapy.

It has now been demonstrated that antidepressants may also help to address these biases, and appear to do so much earlier than they affect mood.<sup>38</sup> Using modern neuropsychological techniques, 35 it is possible to measure these changes in biases in a standardised way and correlate them with changes in brain activity. For example, seven days of antidepressant treatment in healthy volunteers results in measurable increases in positive biases, such as reduced recognition of negative facial expressions.<sup>39,40</sup> These findings have also been correlated with reduced brain activity in regions associated with threat, such as the amvadala.41 Similar changes have even been reported after single doses of the antidepressant citalogram, given both intravenously and orally. 42,43 A similar effect has been demonstrated in patients suffering from depression. 44,45 For example, in one randomised double-blind placebo-controlled trial, patients with depression and controls were given either a single dose of the antidepressant reboxetine or an inactive placebo.<sup>44</sup> In the patients who were given reboxetine, the negative biases in information processing recorded before treatment were reversed three hours after dosing. Despite the changes in bias, in none of these studies was there a resultant subjective change in mood, suggesting that altering emotional processing may be an early effect of antidepressant treatment. Building on this work, studies have shown that measurable early changes in emotional processing may be a predictor of later clinical response<sup>46</sup> and can be used to determine whether novel drugs can act as antidepressants. 47,48

Neuropsychology is one area of research that has specifically focused on the bridging of biology and psychology. The work presented here demonstrates that it is possible to develop robust and standardised ways of measuring certain psychological aspects of mental illnesses within a biological

framework, and to use these findings to develop biomarkers of disease and treatment response.

#### **Genetics**

In the past decade our knowledge of psychiatric genetics has expanded greatly. Alongside rapid advances in genetic technology, recent successes are largely attributed to large-scale international collaborations in the field. <sup>49,50</sup> The Psychiatric Genomics Consortium (PGC), for example, represents a collaboration of hundreds of scientists working in 19 different countries and over 60 different academic institutions. <sup>51</sup> Such collaborations allow groups to share methodology and data from genome-wide association studies (GWAS) and studies of genomic structural variation, to improve the power and accuracy of their analyses. This approach is called 'genome wide' because it assesses all the genes of a single individual at the same time.

GWAS are designed in a similar way to classical case control studies. Their aim is to detect small changes to the genetic code, called single nucleotide polymorphisms (SNPs), and see whether they are associated with disease cases. To date the PGC has reported the findings of large GWAS analyses in four major disorders: major depression,<sup>52</sup> bipolar affective disorder (BPAD),<sup>53</sup> schizophrenia<sup>54</sup> and attention deficit hyperactivity disorder (ADHD).51,55 In the analysis of BPAD, over 11,000 patients were compared with over 51,000 controls. 53 This analysis found a significant association between BPAD and SNPs in a number of genes, including CACNA1C, which is associated with calcium channel function, and ODZ4, a gene implicated in cell signalling and neuronal path finding. Similarly, seven SNPs, including in the miR-137 gene, a regulator of neural development, were found to be significantly associated with schizophrenia.<sup>54</sup> In a 'crossdisorder' analysis, the PGC also demonstrated that certain genes, including CACNA1C, might actually be associated with more than one disorder.<sup>56</sup> Surprisingly, in the study of major depression, despite the inclusion of over 18,000 patients, PGC researchers were unable to find any statistically significant findings. Similarly, analyses of GWAS data by other large international collaborations found no reliable SNPs that predict treatment response to antidepressants. 57,58 The authors of the PGC study cite a number of potential reasons for the lack of findings in depression.<sup>52</sup> First, compared with the prevalence of depression in the community, the sample size may still be too small to detect results. Second, depression may be particularly heterogeneous, both clinically and aetiologically. Finally, the authors raise the possibility that an interaction between risk genes and environment stressors may be particularly important in the manifestation of depression, and as such the GWAS approach may not appropriately capture this form of 'genetic architecture'.

Alongside small genetic changes like SNPs, research has also demonstrated that much larger structural variation in the genome may be important in psychiatry. <sup>59,60</sup> So-called copy number variations (CNVs) result in cells having an abnormal number of copies of large sections of DNA. These regions vary in size, from over 1,000 DNA base pairs to millions, and

are thought to account for 13% of the human genome. 61 In autism, assessments of CNVs have found abnormalities in a number of genes, such as NRXN1,62 which is associated with cell adhesion in the nervous system. It is now estimated that there may be over 200 CNVs associated with autistic spectrum disorders.<sup>62</sup> Notably this area is one example of work that has already begun to be translated into the clinical field, where chromosomal 'microarrays' (tools capable of detecting clinically relevant CNVs) are now recommended in the clinical assessment of some patients with autism. 63 Similarly a variety of CNVs, such as the deletions at 22q11.2 and duplications at 16p11.2, have been discovered to be associated with schizophrenia.<sup>64,65</sup> It has been argued that, given the prevalence of CNVs in patients with schizophrenia,66 the use of clinical microarray testing should also find a role in the assessment of these patients in the near future. 64,66 In keeping with the cross-disorder GWAS data, analyses show that some CNVs, such as deletions in NRXN1, are associated with more than one form of mental illness.64

Alongside these changes to the DNA code, it is now recognised that the external environment can also have an impact on gene regulation, and that these changes can be inherited.<sup>67</sup> These effects can happen without altering the underlying DNA sequence and so are referred to as 'epigenetic'.68 Molecular mechanisms of epigenetic changes include the methylation of DNA and histone modification - that is, the addition of small chemical groups to the DNA and the associated proteins. Again, this research area has been instrumental in encompassing the biological, psychological and social aspects of a patient's difficulties by bridging genes and the environment. 69 For example, one study found differences in DNA methylation in genes such as ALS2 in the hippocampal tissue of people with a history of severe childhood trauma when compared with controls. ALS2 controls a broad spectrum of cellular and molecular processes, including signalling cascades, neuronal morphogenesis, axonal growth and neuroprotective processes.<sup>70</sup> Moreover, recent papers have implicated epigenetic changes in the 'glucocorticoid receptor' as a key mechanism in regulating the stress response, a fundamental means by which early exposure to life stressors permanently changes stress reactivity.71,72 There is also some evidence that epigenetic mechanisms may be important in determining treatment response to antidepressants.73

As mentioned earlier in this section, the lack of consistent genetic findings in the GWAS of depressed patients has been partly explained by the fact that 'gene—environment interactions' (GxEs) might be more important than genetic effects alone. Indeed, the concept of GxEs is one more methodological approach that allows the integration of biological and psychosocial factors in a single model. Within this framework, perhaps the most important finding is the notion that life stress induces psychopathology only in a subgroup ofpatients, whose vulnerability is in part due to their genetic make-up. Moreover, while we have known for many years that specific genetic variables only increase the risk of psychopathology when challenged by specific environments

(that is, life stressors),<sup>74</sup> recent studies have examined the molecular mechanisms underlying these GxEs. For example, a recent paper has shown that a functional polymorphism in the FK506 binding protein 5 (FKBP5) gene, an important regulator of the stress hormone system, increases the risk of developing stress-related psychiatric disorders by regulating DNA demethylation in response to stress.<sup>75</sup> These kinds of studies may help to explain why genetic findings, to date, do not fully explain the estimated heritability of most mental illnesses.<sup>76,77</sup> Taken together with the 'epigenetic' studies described above, this area of research has potentially profound public health implications, as it clearly highlights the primacy of individual vulnerability or resilience (determined by a combination of genetic make-up and early life experience) in the trajectory to the development of mental illness(es).

In summary, the emerging picture is that many psychiatric disorders have complex genetic underpinnings. It appears that genetic risk factors do not follow conventional diagnostic boundaries and there are few genes that are either necessary or sufficient to cause disease on their own. In many cases, multiple genetic risk factors, combined with important social and psychological stressors, place people at risk of developing mental illness. Identifying and understanding genetic contributions to mental illness is likely to have a role in developing our understanding of diagnoses in psychiatry, identifying those at risk of developing illness and potentially helping to guide treatment.

#### **Blood-based biomarkers**

Developing reliable blood tests for mental illnesses would represent one of the most significant advances in psychiatric practice. Ideally such tests would aid in diagnosis and in the prediction and monitoring of treatment response. A major focus for the development of blood-based markers, especially in depression, has been the interplay between the stress response and the immune system.

Meta-analyses have shown that depression is associated with measurable increased activity in the hormonal stress response systems, also called the hypothalamic-pituitary-adrenal axis,78 and with measures of inflammation, such as C-reactive protein (CRP),79 interleukin-6 (IL-6) and tumour necrosis factor.80 In recent studies, psychosocial risk factors for the future development of mental illnesses, such as an experience of early life trauma or of socio-economic disadvantages, have been found to be associated with increased inflammatory biomarkers in adulthood. Elevated blood levels of CRP in otherwise healthy and euthymic individuals have also been found to be associated with the subsequent development of depressive symptoms, 81 supporting the notion that increased inflammation may be on the causal pathway to depression. Importantly, this notion is also supported by recent clinical trials showing that anti-inflammatories may have an antidepressant action.82 Furthermore, in a recent clinical trial of the anti-inflammatory drug infliximab in treatment-resistant depression, only the subset of patients with raised inflammatory markers showed some response to this treatment.83

The mechanism by which both the stress response and inflammation could contribute to the development of depression may be related to the inhibition of neural growth factors like brain derived neurotrophic factor (BDNF) affecting neuroplasticity in the brain.<sup>84</sup> For example, a recent study examining the effects of early life trauma on structural changes in the brain showed that a smaller hippocampus was linked with higher levels of IL-6 and lower levels of BDNF.<sup>85</sup> This emphasises the importance of blood-based biomarkers in our search for the potential mechanisms by which psychosocial factors affect brain function and lead to mental illnesses.

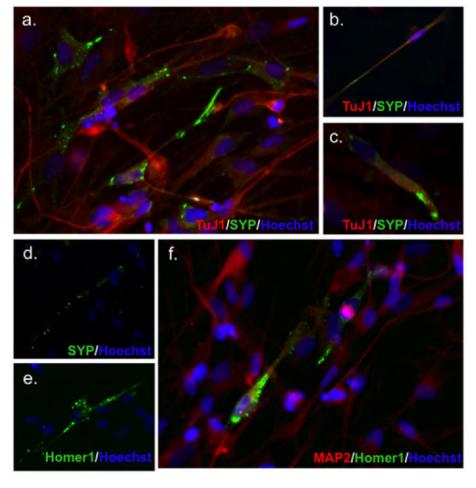
One biomarker technique recently used in psychiatric research is the measurement of gene expression in the blood. By measuring the levels of messenger RNA (mRNA) in blood cells, it is possible to establish which genes are being expressed and to what extent. This appears to be particularly promising in the development of blood-based biomarkers for depression. <sup>86</sup> For example, one group measured the gene expression of 15 different genes associated with stress, inflammation and neuroplasticity in patients with depression, before and after they had treatment with antidepressants. <sup>87</sup> They found that, of the 15 genes, high baseline levels of mRNA in three genes associated with inflammation (IL-1 $\beta$ , MIF and TNF- $\alpha$ ) predicted a poor response to treatment. Symptom reduction, however, was associated with changes in the level of expression of other genes, such as a reduction

in IL-6 (also associated with inflammation) and an increase in neural growth factors, including BDNF.<sup>87</sup> These findings are too preliminary to implement into current clinical practice. However, it is possible to envisage a future where bloodbased biomarkers, such as peripheral gene expression, guide clinical decision-making regarding antidepressants and help us identify patients early on who may not respond to first-line treatments.

#### **Pre-clinical models**

Using pre-clinical models (i.e. animal or cellular models) is an important approach in neuroscience research relevant to mental illness. The ultimate goal of such research is to uncover the fundamental biological processes that lead to states of illness, changes in behaviour or responses to medications. Examples include studies where rodents are exposed to stressors that are mild but unpredictable, thus resembling human life experience, or where in vitro brain cells are exposed to stress hormones or to antidepressants in their culture medium. These techniques are vital for developing our understanding of these conditions and for drawing up new targets for medications. Obviously the findings and predictions of these 'pre-clinical' models have to be tested and validated in humans before they can be presumed to apply to patients suffering from mental illnesses. As an example of this validation process, the epigenetic changes mentioned above to the FKBP5 gene in patients exposed to

Figure 3.2 Multipotent, hippocampal progenitor cell line HPC03A/07, stained with synaptic markers and hippocampal granule cell markers.



early life stressors resemble findings from models of rodents exposed to environmental stress and nerve cells exposed to stress hormones.<sup>75</sup> Similarly, a recent study found an increase in the stress-related protein SGK1 in the blood of patients with depression. The same protein has been found to be increased in the brains of animals exposed to stress and in nerve cells exposed to stress hormones.<sup>88</sup>

Understanding how medications work at a cellular and molecular level would not be possible without the use of pre-clinical models. Equally, these approaches are vital for identifying new molecular targets in the disease process for the development of novel medications. For example, it has recently been demonstrated that ketamine, an anaesthetic, has rapid antidepressant effects in patients with treatment-resistant depression.89 Unfortunately, due to concerns over its safety, the potential for abuse and its ability to induce psychotic symptoms, ketamine is of limited use clinically. Researchers are therefore trying to understand how ketamine causes its antidepressant effects, in order to develop novel and safe antidepressants for clinical use that lack the dangerous side-effects of ketamine. Using animal models of depression, it has been shown that ketamine activates a signalling pathway within cells known as the mammalian target of rapamycin (mTOR) pathway.90 Blocking the mTOR pathway results in the loss of the antidepressant effect of ketamine, demonstrating that it is crucial for this effect. 90 Moreover, it has been shown that the production of the neural growth factor BDNF is also crucial for this antidepressant action,<sup>91</sup> as mice genetically unable to produce BDNF do not respond as well to ketamine. Finally, and as an example of the translational pathways mentioned above, a recent study has shown that patients with depression who have the same BDNF genetic mutation as the mice models were also poorer responders to ketamine. 92 Aside from BDNF, other animal models have shown that the inhibition of an enzyme called GSK-3 $\beta$  is also important in the antidepressant response to ketamine. 93,94 This enzyme is believed to be involved in a process that leads to a reduction in the number of connections between neurons, called 'synaptic pruning'. These studies demonstrate that using pre-clinical models to elucidate some of the mechanisms of action of ketamine have yielded a number of molecular targets on which novel antidepressants could be based.

Developing models that take into account the complex genetic architecture of psychiatric conditions is also crucial in understanding pathophysiology and developing novel treatment targets. Human neurons obtained from embryonic tissue can be used to identify molecular mechanisms activated by 'depressogenic' stimuli and antidepressant drugs.<sup>95,96</sup> The two studies mentioned above that exposed neurones to stress hormones used this approach.<sup>75,88</sup> However, this field will truly be revolutionised by the development of induced pluripotent stem cells (iPSCs), which represents a major advance in our ability to develop cellular models. Yamanaka and colleagues (2006) demonstrated that it was possible to reprogramme a specialised cell taken from an adult organism into a stem cell – that is, a cell that

can then be reprogrammed into any type of cell in the body, including neurons.<sup>97</sup> By making these cells express specific 'transcription factors' that regulate protein synthesis, they were able to demonstrate that both mouse<sup>97</sup> and human skin cells called fibroblasts98 could be converted into stem cells. Using this technique, it is possible to take cells from the skin of a patient and produce stem cells that retain the patient's genetic make-up. These iPSCs derived from patients can then be stimulated to become functional nerve cells. Since this discovery, iPSCs have been used to model a number of different conditions, such as spinal muscular atrophy99 and Rett's syndrome.<sup>100</sup> In psychiatry, iPSCs have so far successfully been derived from patients with schizophrenia. In one study they were derived from two siblings with schizophrenia who shared a rare associated mutation in the DISC-1 gene.<sup>101</sup> It has also been shown that it is possible to convert iPSCs derived from patients with sporadic schizophrenia into functional neurons,<sup>102</sup> including dopaminergic neurons.<sup>103</sup> These early studies have found evidence of abnormal neuronal function, as shown by decreased neurite numbers (that is, less cellular ramification) and decreased connectivity in neurons derived from patients. The use of this technology to model disease is in its infancy, but it remains one of the most exciting areas for medical research.

It is undoubtedly difficult to truly replicate mental illnesses using pre-clinical models, and this may be one of the reasons why drug discovery in psychiatric disorders is slower than in other fields of medicine. However, it is impossible to understand the molecular and cellular mechanisms underlying psychiatric conditions such as autism and schizophrenia without these approaches. Equally, identifying new targets for treatment and testing their safety prior to their use in patients would not be possible without this type of scientific research.

# Conclusion

The classical psychiatric approach to helping a patient is one that encompasses the biological, psychological and social aspects of their distress. Neuroscience research does not refute this holistic approach to care, but rather seeks to understand how crucial psychological and social events lead to the development of illness. This approach has yielded important results in recent years and it has only been possible to describe a handful of these findings in this chapter. There is now an urgent need to translate this work into improved care for patients suffering from psychiatric conditions. This is likely, however, to be a challenging process and not all discoveries will impact on patient care. Further, successful translation requires more academic training in neuroscience-based psychiatric research and increased research funding to levels matching the disease burden. In particular, neuroscience research will not deliver improvements to patient care unless there is institutional support for the whole process by which promising early findings are tested in humans, first through proof-of-concept studies and then through larger clinical trials. Finally, we need to be aware that the 'biological model' on its own does not seem to have delivered an improved public perception of mental illnesses. Therefore, combating the stigma that dogs mental illness may require a balanced and integrated bio-psycho-social model – one that both explains how psychological and social factors affect brain function and defends the importance of the individual's choices and freedom.

# Authors' suggestions for policy

- When compared with other health problems, there is a mismatch between the societal costs of mental illnesses and the funding going into research and development for new therapeutic approaches. This has recently been further exacerbated by disinvestment by pharmaceutical companies.
- Neuroscience research is not antithetic to the psychosocial model of mental illness, and some of the most exciting research in this area is specifically focused on the understanding of how psychosocial factors affect brain mechanisms.
- Some of the approaches described in this chapter will deliver clinical benefits, especially in refining 'personalised treatment' for individual patients. However, translating neuroscience research into patient benefits requires sustained support of clinical studies testing these new approaches.
- Integrating neuroscience research within a bio-psychosocial model of mental illness could not only foster better acceptance of treatment but also reduce stigma, something neuroscience research alone seems unable to do.

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## Chapter 4

# Technological innovations in mental healthcare

#### **Chapter authors**

Chris Hollis<sup>1</sup>, Jennifer Martin<sup>2</sup>, Sarah Amani<sup>3</sup>, Rebecca Cotton<sup>4</sup>, Mike Denis<sup>5</sup>, Shon Lewis<sup>6</sup>

- 1 Clinical Director, NIHR MindTech Healthcare Technology Co-operative, Institute of Mental Health, University of Nottingham
- 2 Programme Manager, NIHR MindTech Healthcare Technology Co-operative, Institute of Mental Health, University of Nottingham
- 3 Chief Clinical Information Officer, Surrey and Borders Partnership NHS Foundation Trust
- 4 Director of Policy, Mental Health Network, NHS Confederation
- 5 Director of Information Strategy, Oxford Academic Health Science Network
- 6 Director, Institute of Brain, Behaviour and Mental Health, University of Manchester, Manchester Academic Health Science Centre, Manchester Mental Health and Social Care Trust

#### Key statistics

In 2013<sup>1</sup> in Great Britain:

- 36 million (73%) of those aged 16 years of age and older accessed the internet every day (20 million more than in 2006).
- 61% of those aged 16 years of age and older accessed the internet with a mobile phone or portable computer, this rises to 94% for those aged 16-24.
- 72% of those aged 16 years of age and older bought goods or services online (up from 52% in 2008).
- 43% of those aged 16 years of age and older used the internet to seek health-related information.

#### Summary

Advances in technology and particularly mobile digital information and communication technology (ICT) continue at an exponential rate, making it possible to communicate, obtain information and access and buy goods and services in new ways. Technology offers the potential to transform mental healthcare delivery through widening access to information and services, offering adherence support and real-time symptom monitoring that allows earlier and more timely interventions and new treatments such as non-invasive neuormodulation for depression and psychosis. Advances in sensor technology, on-line psychological therapy and remote video consultation, mobile apps and gaming represent real opportunities to engage and empower patients with mental health problems. To make the most of these opportunities, however, and ensure the trust of the wider public, it is essential that technologies target unmet clinical needs, have a strong evidence base and that patients are actively involved throughout the development process. Clinicians must also be active partners in the development, evaluation and implementation of new technology to ensure that it is viewed as a way of improving their practice rather than being a challenge to their skills and roles.

## Technological transformation in mental health services

Mental health disorders are the single largest cause of disability in the UK, affecting 1 in 4 people over their lifespan² with an estimated cost to the economy of £105bn per year.³ The growth in demand for mental healthcare is exceeding available NHS resources, and this gap is likely to increase up to 2020. Cost pressures require that more is done for less and providers therefore must find innovative ways to deliver services. Technology has the potential to transform mental health service delivery through earlier detection and diagnosis and by making effective interventions available to more people. For example, CBT (cognitive behaviour therapy) for anxiety and depression delivered online and in real-time by a therapist has been shown to be effective and

acceptable to patients. There is also a strong economic case for innovative and preventative approaches to mental health, with increasingly robust evidence suggesting that costs can be reduced by improving outcomes and increasing quality and productivity.<sup>4</sup>

The terms eHealth and mHealth (increasingly collectively referred to as "connected health") describe the delivery of healthcare by electronic means via the internet using a variety of devices including mobile phones, remote monitoring devices and other wireless devices. These digital technologies can greatly improve access to mental healthcare and treatment adherence by enabling services to be delivered more flexibly and tailored to individual patient needs. The Government's mental health strategy 'No health without mental health' recommends the increased use of ICT to improve care and access to services.

In January 2013, the Mental Health Network at the NHS Confederation published a discussion paper 'E-mental health: what's all the fuss about?'.<sup>6</sup> This asked how policy makers, practitioners, patients and providers of mental health services can make the most of the opportunities offered by technology to not just improve efficiency, but to transform the very nature of mental healthcare.

E-mental health can support cultural change in services, empowering patients to exercise greater choice and control. For example, the provision of on-line psychological interventions, potentially accessible 24/7, is increasing rapidly using synchronous video/voice or asynchronous text communication. Examples of providers to the NHS include *Xenzone*, *PsychologyOnline* and *Big White Wall (BWW)* (see Box 4.1).

In mental healthcare, assessment and diagnosis is still largely based on subjective clinical judgements about symptoms and behaviour. Technological innovations have the potential to bring more objectivity and reliability to these processes of assessment, diagnosis and monitoring. However, despite major advances in the neuroscience of mental disorders, technologies informed by this understanding are only just beginning to be translated into individual patient assessment and treatment.

In addition, mental health professionals have historically been reliant on face-to-face consultations in clinic settings away from the normal lives of their patients. Mobile applications (hereafter 'apps') are now available that allow patients to record their mood, behaviour and activities in real-time using well validated measures such as the PHQ-9 depression scale. Patients can track their condition using their own mobile device over time and share this information with their clinician. Potential benefits to patients include greater engagement in their care and earlier detection of problems, more timely adjustment of treatment and shared decision making. Sensors such as

a The World Health Organization (WHO) defines e-health as "the transfer of health resources and healthcare by electronic means" and mHealth as "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants and other wireless devices".

accelerometers, gyroscopes, microphones and cameras, which are now standard parts of smartphones and other mobile devices, mean that it will be possible to continuously and passively collect objective data that can give additional insight into a person's behaviour and activities. For example, detecting subtle changes in sleep and activity patterns constitute important early warning signs of relapse and can prompt early intervention in depression and bipolar disorder.<sup>7</sup>

ICT has the potential to address issues such as social isolation and the relative inaccessibility of mental health services to young people. The rapid increase in popularity of social media platforms means that people are increasingly able to access information and support from peers and professionals in new and informal ways. Mental health problems disproportionately affect younger people, yet this group is also the biggest user of ICT; social media may widen access for groups who find it difficult to access traditional services.

It is critical, however, to consider the challenges of introducing new technology to mental healthcare. The so-called 'digital divide', where there is a gulf between those who have ready access to personal computers and the internet and those who do not, means that some groups of patients (e.g. older adults, persons who are homeless and people with intellectual disabilities) could experience greater barriers to accessing mental healthcare delivered using ICT.

## Data protection, privacy and security: establishing public and patient consensus

Maintaining public trust when handling and sharing personal health data is paramount and this requires serious public engagement over issues of consent, data security and privacy. There is an even greater need to address these ethical issues in the field of mental healthcare as the data is often highly sensitive personal information. Initiatives such as 'Digital First' from the Department of Health, which aims to reduce unnecessary face-to-face contact between patients and healthcare professionals, are encouraging NHS trusts to replace these unnecessary face-to-face contacts with video-based remote consultations. It is essential, however, that these initiatives do not overlook rigorous evaluation of clinical benefit, user experience, safety, security and privacy.

Although technological developments hold great promise, public acceptance and adoption to scale are unlikely unless steps are taken to safeguard the legal and ethical rights of the public and patients. It has been argued that a social contract for serving the common good by advancing knowledge should be developed.<sup>8</sup> The Case Records Interactive Search (CRIS) system, which is described in detail later in this chapter, is an example of how this has been shown to work at a local level. This system was developed in partnership with, and is operationally managed by, patients.<sup>9</sup>

#### Box 4.1 Case Study – Big White Wall

Big White Wall (BWW) is an award winning digital mental health and wellbeing service, designated a 'High Impact Innovation' by the NHS. It delivers personalised pathways for conditions that include depression, anxiety and Post-Traumatic Stress Disorder (PTSD) as well as issues such as alcohol use and weight management. Therapeutic services are available 24/7 via mobile, tablet and PC and over 17,000 people have used the service.

BWW works alongside many NHS organisations and its services currently cover 24% of the UK population. Wandsworth Clinical Commissioning Group (CCG) have reported that users using BWW's online therapy service have experienced a 58% recovery rate compared with 46% for other services (the UK target is 50%). 92% of clients were satisfied with their treatment, with 100% satisfaction with BWW's therapists.

In 2013, GPs began to prescribe direct access to Big White Wall 'LiveTherapy' provided online by clinicians and therapists via real time video, audio or text support. Dr Aryan Lawe, Wandsworth Medical Centre said, "In a busy consultation, patients are impressed when you type in their email and their smartphones instantly receive an email allowing access to Big White Wall. The service, for most patients, offers a whole host of strategies in dealing with many psychological problems and, importantly, it has no waiting lists."

Rebecca Cotton (NHS Confederation) and Sharon Makin (BWW)

#### Digitalisation of society

2013 data<sup>1</sup> show that 73% of adults (people aged 16 and over) in the UK access the internet every day and 72% of all adults buy goods or services online. Access to the internet using a mobile phone more than doubled between 2010 and 2013 to 53%. 51% of UK adults now own a smartphone (almost doubled from 2011) and 24% own a tablet.

Significant sections of society are becoming increasingly familiar and comfortable with using technology for a wide range of transactions. Half of all adults (18 years and older) and more than three-quarters of 25-34 year olds use online banking. In 2013, 43% of adults (18 years and older) used the internet to seek health related information, an increase from 18% in 2007.<sup>10</sup> A recent study of mental health patients found that their use of technology (computers, mobile and smartphones) was similar to the general population, with older people reporting less familiarity, access and confidence with these technologies.<sup>11</sup> Older people experiencing psychosis reported a significant desire to increase their use of computers, suggesting a cost and skills gap, rather than indifference, is the reason for lower rates of computer usage.<sup>11</sup>

Rapid developments in ICT have resulted in an established and growing global mHealth market, estimated to be worth US\$2billion in 2013.<sup>12</sup> In the UK, initiatives such as the Technology Strategy Board and Small Business Research Initiative support small and medium sized enterprises to enter this field and develop technological solutions to address unmet mental health needs.

#### mHealth apps

The last five years have seen a rapid increase in the number of mobile healthcare applications (mHealth apps), including many targeted at mental health. Some of these are aimed at healthcare professionals but the majority are targeted at the general public although many are developed without significant user (patient or clinician) involvement.<sup>13</sup> The developers of these include commercial enterprises, third sector organisations, NHS trusts and staff as well patients themselves. The majority of these are sold via commercial

## Box 4.2 mHealth support for people with serious mental illness

Serious mental illness (schizophrenia, bipolar disorder) affects 1% of people, usually starts in early adulthood and in most people carries lifelong disability and episodes of relapse which often require unscheduled inpatient care. Early intervention for the first episode, and early detection and intervention for later relapses, increases the chances of better health outcomes. Funded by consecutive Medical Research Council grants since 2010, ClinTouch (www.clintouch.com) is a personalisable mobile app for serious mental illness, developed in close conjunction with patients, that aims to enhance user self-management, improve the experience of received care and to facilitate early detection and intervention for relapse. ClinTouch enables users to track their symptoms during the day with the data uploaded in real-time to a central server. Feasibility trials have shown that the system is safe, provides valid data, is easy to use and is liked by users.57,58

The full, end-to-end system has now been built into Trusts in Manchester and London, where real-time data summaries are entered into e-care records and staff alerted if symptoms suggest deterioration, allowing for preventative action. Medication management, social networking and other functionality can be included. *ClinTouch* appears to empower users by enhancing self-management, and improves their experience of collaborative care, with *ClinTouch* processes part of individually-agreed care and crisis plans. Reducing unscheduled inpatient care for relapse by 10% would save a Trust £0.5-1m per year.

Shôn Lewis, John Ainsworth, Caroline Sanders

## Box 4.3 Identifying unmet needs and co-creating solutions with end users: the My Journey app

The Early Intervention in Psychosis (EliP) service in Surrey and Borders Partnership NHS Foundation Trust has worked with young people (14-35 years of age) since 2009 to develop technologies to enable better access to services and information. This was in response to feedback from young people that they required more information about services and wanted to access this information on their mobile phones.

"I am someone who has gone through the whole journey from being admitted to all the aftercare services of all the kind of different mental health services... The NHS did give me what I needed but what's lacking is the correct information being cascaded down to me as a young person to potentially prevent that stage that I got to. We need more focus on communicating directly with young people."

Quote from young person involved in the project

The *My Journey* app is the first health app for first episode psychosis. The design of the app was based on what young people said they wanted from an app, which included appointment and medication reminders and the ability to track their symptoms and share their progress with people who they deemed important in their recovery. It was also based on the evidence for effective interventions in psychosis: recovery orientated psycho-education<sup>59</sup> and self-reporting symptoms to prevent relapse<sup>60,61</sup> that has shown how providing tips and strategies can help foster wellness, shared decision making and increased involvement of young people in the self-reporting of early warning signs. (See example image of 'My Journey' app in this chapter.)

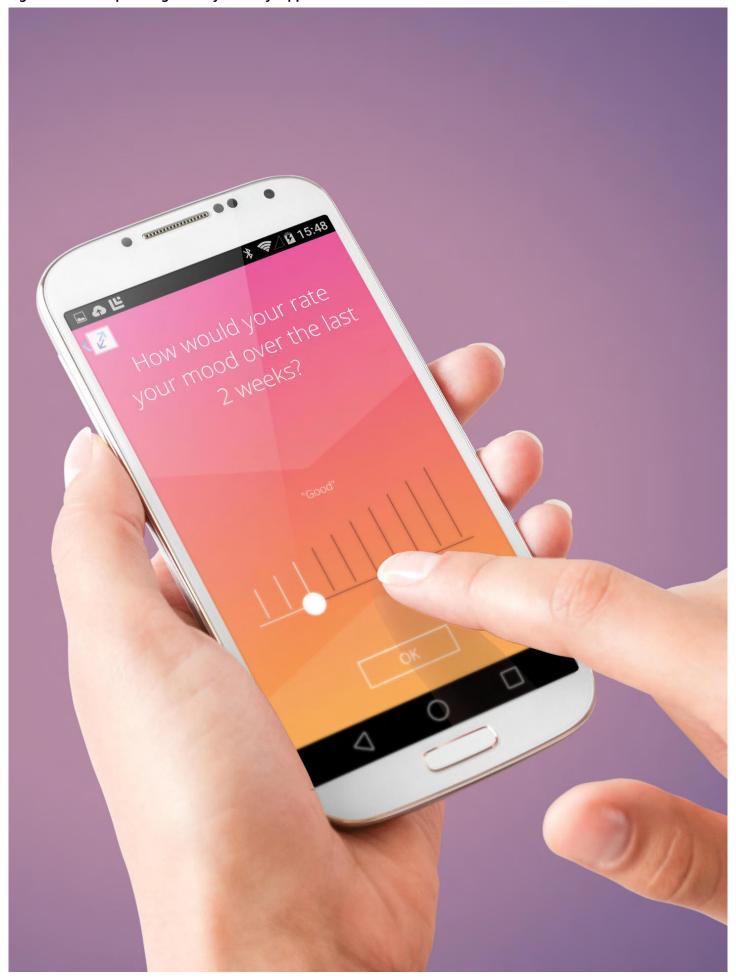
Sarah Amani

marketplaces but the NHS has also established a health apps library, which contains (as of 31st August 2014) 17 apps categorised under mental health.

The relative low cost and speed with which mHealth apps can be developed and placed on the market poses a challenge for NHS and regulatory bodies. Guidance on the regulatory requirements for mHealth apps was published by the Medicines and Healthcare products Regulatory Agency (MHRA) in March 2014<sup>14</sup> and NHS England is currently working with the US Food and Drug Administration on a bilateral framework for regulation of mHealth apps.

Examples of mHealth apps that have been developed for mental health include ClinTouch (see Box 4.2), My Journey (see Box 4.3), Buddy App, and WellHappy. Typically, these apps include a symptom tracker and diary function, appointment and medication reminders and motivational prompts. These examples have been developed with

Figure 4.1 Example image of 'My Journey' app



significant user and clinician involvement and incorporate evidence-based principles of care (e.g. early-intervention improves outcome in psychosis). Although early-stage pilot evaluations suggest that these apps are safe and their use is acceptable to patients and clinicians, further research is needed to demonstrate clinical and cost-effectiveness at scale in routine NHS settings. Although early-stage pilot evaluations suggest that these apps are safe and their use is acceptable to patients and clinicians, further research is needed to demonstrate clinical and cost-effectiveness at scale in routine NHS settings. It is clear that it is necessary to build an evidence base and framework for evaluating the rapidly increasing number of mHealth Apps and other digital products.

#### Games for mental health

According to Granic,<sup>15</sup> 'Gamification' is the use of 'smart' computer games to motivate behaviour change. There is a small body of research that indicates potential mental health benefits in the use of computer games and proposes some candidate mechanisms by which playing video games may foster real-world psychosocial benefit.<sup>15</sup>

Research at the University of Nottingham involving young people aged 10-12 years of age with behavioural problems has shown that games can be effective in engaging young people with their therapists to discuss their reaction to situations met in the games. <sup>16</sup> A more recent development is the ability to include 'affective' controls in the games. This will allow the game itself to look at the emotional response of the player to the situations they are working in. This gives the therapist a novel insight to the patient's reasoning processes. <sup>17</sup>

## Automated objective assessment and monitoring

#### Mood disorders and depression

Affective Computing is 'computing that relates to, arises from, or deliberately influences emotion or other affective phenomena', while Social Signal Processing addresses all verbal and non-verbal communicative signalling during social interactions. Both involve measuring aspects such as smile intensities, speech rate, or tone of voice using suitable audio and/or video recordings. On the support of the suppo

The most obvious application of this technology is in mood disorders, whether in the community or in the clinic. Monitoring interactions with family members or virtual humans could alert the patient, and potentially their clinician, of an impending episode of depression. Another application could be in monitoring treatment response, where home observation could provide a more fine-grained measure of affect than is currently possible.

The winners of the recent Audio-Visual Emotion Recognition Challenge, <sup>22,23</sup> which included a task to automatically detect the severity of depression, found that automated analysis of

facial expression corresponded sufficiently closely with clinical ratings of depression (Beck Depression Inventory-II (BDI-II)) to suggest that there is both theoretical underpinning and practical evidence for the effectiveness of this technology. However, despite its potential, this technology has not yet been tested in a clinical setting or integrated in an intervention in medical practice in the UK, which would be the logical next step in the development of this technology.

#### **Attention Deficit Hyperactivity Disorder (ADHD)**

The assessment and monitoring of ADHD normally relies on the subjective interpretation of information gained through clinical interview and standardised rating scales such as psychometric tests. Objective computerised neuropsychological tests can avoid subjective observer bias in traditional diagnostic assessment and measures of treatment response.<sup>24</sup> One such neuropsychological test is the continuous performance test (CPT), a computer-based programme that measures attention and impulsivity during a sustained task. QbTest (Qbtech Ltd) is a novel CPT, which in addition to measuring inattention and impulsivity, also includes infra-red motion analysis to objectively measure motor activity throughout the test, thereby also providing a measure of hyperactivity. QbTest has been shown to reliably differentiate children and adults with ADHD from controls24-26 and can provide a good measure of treatment response, with the potential for speeding up treatment optimisation.<sup>24,27</sup> Following promising initial research, 28,29 the clinical utility of QbTest in routine NHS practice is currently being evaluated by the NIHR CLAHRC (National Institute for Health Research, Collaboration for Leadership in Applied Health Research and Care) East Midlands through a randomised controlled trial of feedback of test results to clinicians<sup>30</sup> to determine whether Obtest reduces the number of clinic visits required to make an accurate diagnosis of ADHD.

## Neuromodulation technology in mental health

Transcranial magnetic stimulation (TMS) involves administrating repetitive magnetic pulses to a focal region on the scalp to stimulate (or depress) the underlying target brain region and the brain networks connected to the stimulated region. It has developed significantly since its inception in 1985<sup>31</sup> and was recently included in the NICE pathway for headaches as an interventional procedure that can be offered in specialist clinics for the management of migraine.<sup>32</sup>

TMS applied to the dorsolateral prefrontal brain region has been shown to be effective for patients who fail to respond adequately to antidepressants.<sup>33,34</sup> Whilst the efficacy of TMS in depression was previously questioned on the basis of studies published before 2005 that were notably underpowered with suboptimal stimulation, it is now clear that more recent studies with improved administration and larger samples demonstrate consistent efficacy.<sup>35,36</sup> In fact, the size of treatment effect of pharmacotherapy,

#### Technological innovations in mental healthcare

psychotherapy and TMS are of comparable magnitude (0.3 to 0.4 in depression).<sup>33,37</sup> In a recent meta-analysis, 29.3% of patients receiving active TMS responded and 18.6% remitted when compared to 10.4% response rate and 5% remission rate with sham TMS.<sup>38</sup> TMS is sometimes considered as an alternative non-invasive option to Electroconvulsive Therapy (ECT) for severe depression, although head to head comparisons demonstrate superiority of ECT.<sup>39,40</sup> TMS may also be effective for treatment-resistant auditory hallucinations.<sup>33</sup>

TMS treatment requires at least 1 hour of contact 4-5 times per week for 3-4 weeks. Despite this, and despite the transient discomfort, TMS appears to have a high rate of patient acceptability,<sup>41</sup> most likely because it does not require anaesthesia and can be done on an outpatient basis. Furthermore, unlike ECT, TMS is not associated with memory deficits. Positive patient-reported outcomes have been demonstrated in naturalistic clinical settings,<sup>41,42</sup> and significant beneficial effects have been found on both quality of life and general health perception measures.<sup>43</sup>

Uncertainties about the optimum dose, duration, frequency of pulses, and the target region for application have led to variations in clinical efficacy. Computerised neuronavigation may improve efficacy when used in conjunction with brain imaging. 44,45 A major obstacle in the routine use of TMS is cost. 46,47 As highlighted above, the variation in clinical efficacy of TMS is of the same magnitude as the variation found for antidepressant response and for psychotherapy. To put this in perspective, the NNT (number needed to treat) for TMS is 4 or 5,48 which is comparable to the pharmacological treatments currently used for most major medical conditions. 49 Prospectively identifying putative treatment responders may help select TMS responders, improve response rates and thus reduce the overall cost of TMS use. Work in this area is ongoing within the NHS. 50

## The 'Big Data' challenge for mental health

Digital health technologies, including for example, electronic medical records, e-prescribing and the increasingly prevalent use of connected devices to monitor health, have the potential to generate large amounts of data that could be of considerable benefit to researchers and policy makers. However, much of this data is either not generated in mental health or is not as available as it might be because it is locked in electronic medical records that are inaccessible for research and detailed analysis.

Broadly speaking there are three processes required to realise the benefit from this potential data: electronic medical records (EMRs), new forms of records that allow direct access from patients (Patient Health Records, PHRs), and pervasive computing and connected devices (mHealth) to enable expansion of the data collected by EMR and PHR as well as to provide other means of data collection. Increasingly data accessed through the EMR is being used within clinical, epidemiological and public health research. In each case, use of the EMR enables scaling of such studies, sometimes by orders of magnitude in both size and speed. Challenges to the use of the EMR in such research are not trivial and include technical (can data be accessed in a format that enables analysis from multiple data sources?), governance (security, privacy, access control) and scientific (is the data of sufficient quality?). However, these challenges are being met both for meta-data such as diagnosis and hospital episodes and patient level data including complex text or narrative data. <sup>51-53</sup>

An example of the use of complex EMR data is the Case Records Interactive Search (CRIS) system established by the Maudsley Biomedical Research Centre in London.<sup>54</sup> CRIS allows researchers to view de-identified records, provided research studies are approved by an oversight committee chaired by a patient and with full user engagement. CRIS users work within the NHS firewall and are contractually obliged to abide by a strict security model. CRIS has been extensively linked to a wide range of health (cancer, mortality, Hospital Episode Statistics, primary care) and non-health (national pupil database) databases. This provides a powerful tool to predict outcomes (mortality, admission, accident and emergency attendance, educational attainment), and CRIS' ability to determine risk of self-harm and other common outcomes is currently being tested, using full details of health record to identify "signals" which might impact service providers. CRIS can also be connected with omics<sup>b</sup> and imaging data to help identify biomarkers for poor prognosis. It provides a powerful tool for health services research allowing the movement of patients between sectors to be studied. The system has been used in many studies, an example being the extraction of data from a single NHS Trust to show substantially increased mortality in people with serious mental illness.51-53

Recognising the importance of accessing aggregated research data, the EU established The European Medical Information Framework (EMIF). This consortium brings together over 60 partners and is establishing IT and governance solutions to a federated access system for data on over 40 million Europeans. It is initially focusing on metabolic disease as a consequence of obesity and Alzheimer's disease.

b 'Omics' refers to the study of biological/molecular data such as the genome (all DNA in a cell) and the proteome (all proteins).

#### Research challenges

## Increasing user involvement and identifying the clinical needs for mental health technology development

It is well established that to be successfully adopted any new healthcare technology must meet the needs of its users, whether they are clinicians, patients, or their families<sup>55</sup> and for mental health technology this is even more important.<sup>56</sup> Healthcare products often arise from an idea of a technology developer or clinician and this can result in products that, although technologically innovative, may not address the most pressing clinical needs of patients. Close user involvement that examines needs and also the priorities of those needs is required from the very beginning, to ensure that the product being developed is not only commercially viable but also provides a tangible benefit to both the user and the health provider.

To address this issue, the NIHR has established Health Technology Co-operatives (HTCs) that aim to identify unmet clinical needs and encourage the development of technologies that meet these needs. The NIHR MindTech HTC (<a href="www.mindtech.org.uk">www.mindtech.org.uk</a>) is working in partnership with patients, clinicians, academics and technology developers to accelerate the development, evaluation and adoption of new technologies in mental healthcare.

## Increasing the evidence-base to support the adoption of technology in mental healthcare

Pragmatic clinical trials are needed to evaluate in 'real world' settings the benefits and risks of implementing new technologies into healthcare systems. These trials need to take into account the user and clinician experience and identify potential barriers and drivers to adoption of the technology with reference to specific clinical conditions and populations. Research is needed to understand better whether psychological and behaviour interventions should be adapted for on-line use including the number and duration of sessions and skills required by therapists when working online.

## Developing common shared platforms and standards for m-Health apps

Currently, most mHealth apps and technologies are developed to operate independently from each other without shared features or interoperability. Development of common standards and platforms will allow data to be safely shared between applications and EMRs. Applications supporting remote consultation and monitoring should be able to work across different conditions (e.g. depression and diabetes) and healthcare providers (e.g. primary and secondary care).

## Developing a framework for patients, clinicians and NHS commissioners to evaluate new technologies

An agreed framework is required to evaluate the core features of new technologies including usability, content, safety, clinical- and cost- effectiveness. This framework for evaluation would clarify what type/level of evidence should be sought from product developers depending on what the specific technology is designed to do and what audience it is targeted at.

#### Conclusion

It has been suggested that digital information and communication technology has the potential to change the face of mental health services and drive efficiencies by increasing user involvement, widening access and encouraging self-management. New developments in automated sensing and monitoring of behaviour and emotion in real-time promise more objective assessment and timely interventions to prevent relapse and hospital admission. Digital mobile and on-line psychological therapies have the potential to massively increase the reach and efficiency of evidence based interventions such as cognitive behaviour therapy for depression and anxiety. However, there is currently insufficient evidence to suggest that this potential is being fully realised, with uptake being limited and outcomes being largely anecdotal and unpublished. There are also major issues to be addressed, the most fundamental of which are patient safety and confidentiality and ensuring that patients and their needs remain at the centre of technology development and implementation. A further challenge is ensuring that the opportunity provided by data sharing between patients, carers and clinicians doesn't threaten privacy and undermine public trust. Finally, patients, clinicians and NHS commissioners require an agreed framework to evaluate the core features of new technologies including usability, content, safety, clinical- and cost- effectiveness.

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## Chapter 5

# Developmental psychopathology: a perspective

#### **Chapter author**

Peter Fonagy<sup>1,2</sup>

- 1 Head of Research Department of Clinical, Educational and Health Psychology and Freud Memorial Professor of Psychoanalysis, University College London
- 2 Chief Executive, The Anna Freud Centre, London

#### Overview

The developmental perspective on psychopathology aims to elucidate the interplay between contextual-social, psychological and biological attributes of normal development across the lifespan and identify precursors and pathways leading to disorder.¹ The approach crucially informs practice in the detection and early intervention of mental health difficulties amongst children and young people from 0 to 18 years old (CYP), as well as helping us to understand the causes and lifetime prognosis of mental disorder. It was crystallised by Sroufe and Rutter² to illuminate the 'origins and course of individual patterns of behavioural maladaptation' and became the dominant framework in child psychiatry in the last decade of the 20th century.³

The focus of developmental psychopathology is not limited to risk and protective factors but is concerned with identifying mediating mechanisms which account for both continuities and discontinuities, indirect and direct causal relationships and the recognition that mental disorders entail multiple processes and need to be understood in terms of multiple risk processes of normal development and pathological adaptation.<sup>4,5</sup>

At the heart of the approach is the intent to identify the developmental pathways associated with greater or lesser likelihood of subsequent psychopathology.<sup>6</sup> In understanding pathways to competent adaptation despite exposure to conditions of adversity, developmental psychopathology prioritises conceptualising resilience and identifying the processes that contribute to positive adaptation in situations that more typically generate maladaptive outcomes. The developmental approach highlights where disorders continue from one phase of development to another (homotypic) and where diagnoses change (heterotypic continuities).<sup>5</sup>

### Risk and protective processes

#### Attachment relationships

The quality of early attachment relationships with caregivers (i.e. the level of the caregivers' sensitivity to the child's experience) has strong and robust associations with child<sup>7,8</sup> and adult psychopathology,<sup>9,1</sup> and shapes the quality of many adult relationships.<sup>10</sup> The quality of care and support at age three predicts with 77% accuracy whether a young person is going to drop out of education by the age of 19.<sup>11</sup> However, some behavioural manifestations, such as social disinhibition and indiscriminate friendliness, associated with early institutional upbringing are more likely to be the consequence of a social dysregulation process than an insecure attachment relationship.<sup>12-14</sup>

#### **Causal environmental effects**

The developmental approach to understanding causation takes advantage of what has been referred to as 'natural experiments'. 15-17 Ingenious designs, such as contrasting egg

donation with sperm donation in looking at the impact of maternal smoking during pregnancy on the development of attention deficit hyperactivity disorder (ADHD), have revealed that smoking had no effect on ADHD and that the association was likely to be genetically, not environmentally, mediated. By contrast, Michael Rutter and colleagues' studies of institutionalised Romanian orphans showed dose-effect relationships between early social (but not nutritional) deprivation and disinhibited attachment behaviour and quasi-autistic features. 19

#### The complexity of genetic influence

Twin and adoption studies have demonstrated that virtually every individual trait is heritable and these influences are stable or increase over development.<sup>20,21</sup> However, developmental studies increasingly show that the apparent increase in heritability of human traits over development can be accounted for by gene-environment correlations (a genetically transmitted trait creating specific environments which reinforce the trait) that lead to increasing differentiation of DZ\* twins relative to MZ† twins; genetically based differences become amplified over time as individuals make choices about exposing themselves to environments to which they have some affinity.<sup>22</sup> Carefully conducted quantitative genetic studies, which simultaneously measure environment as well as zygosity, demonstrate that genetically based personality differences (e.g. low socialisation) influence exposure to contextual risk but it is the exposure to contextual risk which mediates psychopathology such as substance use in late adolescence.23

#### Studies of polymorphisms

Since the 2002 publication of the finding that the presence of the low activity variant of the MAOA gene predicted antisocial behaviour when combined with maltreatment,<sup>24</sup> the literature on gene-environment interactions has grown exponentially.<sup>25</sup> However, there has been controversy and limited success in replicating the MAOA×maltreatment interaction.<sup>26</sup> There is evidence that methylation of the MAOA promoter may be indirectly linked (via MAOA enzyme activity) to self-reported trait aggression.<sup>27</sup> Nevertheless, in general findings from molecular genetics studies, even very large-scale genome-wide association studies have been disappointing.<sup>21</sup> For example, a genome-wide association study of anorexia, with 5,551 anorexia cases and 21,000 controls drawn from 14 countries, reported no findings which reached genome-wide significance.<sup>28</sup>

#### Studies of epigenesis

The literature on the social regulation of epigenetic (chemical modification of DNA) and gene expression is promising because of the influence that stress, intra-uterine factors, maternal nurturing behaviour, nutrition and intra-cellular environment have on these processes.<sup>29</sup> Ten years ago, researchers demonstrated that high-quality caregiving

<sup>\*</sup> Also known as 'fraternal' or 'dizygotic' twins

<sup>†</sup> Also known as 'identical' or 'monozygotic' twins

experienced during the first postnatal week of a rat pup reduced the methylation of DNA associated with the GR (glucocorticoid receptor) gene, which underlies stress responsivity through its regulation of HPA (hypothalamic–pituitary–adrenal axis) activity. This methylation improves expression of the GR gene, enabling the pup to show greater stress resilience.<sup>30</sup> Subsequently we have learnt that the effects of the caregiving environment on DNA methylation are not exclusive to the GR gene<sup>31-33</sup> and can lead to long-lasting alterations in HPA functioning at the level of the hypothalamus.<sup>34,35</sup>

Importantly, replications from human studies of the GR gene are forthcoming in relation to experiences of childhood maltreatment<sup>36</sup> and parental loss or disruption of parental care.<sup>37</sup> These include observations of the hypermethylation or the hypomethylation associated with child abuse of over 300 gene promoters in the hypothalamus.<sup>36</sup> Sexual abuse history linked to antisocial behaviour is associated with hypermethylation of the serotonin transporter gene (SLC6A4).38 The glucocorticoid receptor gene promoter is more methylated in the brains of individuals who had experienced adversity and suicided.39 The NR3C1 glucocorticoid receptor gene was associated with severity of maltreatment based on peripheral blood leucocytes in bipolar disorder<sup>40</sup> and borderline personality disorder.<sup>41</sup> Primary school children who are in institutional care show greater methylation in the promoter region of a number of genes involved in controlling serotonin and glucocorticoid biosynthesis, immune responses, and cell-signalling pathways involved in memory formation.<sup>42</sup> Intriguingly, there is also rodent evidence to demonstrate that epigenetic changes as a consequence of environment are passed on to offspring for three to four generations. 43,44

Taken together, we are now in a strong position to assert that epigenetics are likely to be the key mechanism mediating the impact of social experience to generate behaviour change. This has substantial implications for policy decisions not just in relation to the multigenerational impact of caregiving environments, but also the enduring impact of early physical environment such as childhood diet and chemical exposure, including medication exposure.<sup>45</sup>

#### Parental psychopathology

Recent research has also clarified that the inter-generational association of mental disorder is far more complex than could be reduced to a 'gene versus environment' question. For example, a twin study looking at the association of parental antisocial disorder with childhood psychopathology found that the impact on child depression was environmentally mediated but on ADHD it reflected genetic influence, while the association with conduct disorder was a combination of the two. <sup>46</sup> The impact of the effective treatment of parents with psychological disorder on the child's wellbeing confirms the direct causal influence of parental psychopathology. <sup>47-49</sup>

## The homotypic continuity from children and young people to adult mental disorder

Population-based studies (in the US and New Zealand) show the incidence of mental health problems between the age of 12 and 25 years to be 50%, and 12-month prevalence in the 13 to 18 age group to be 40%. 50,51 The risk of persistence and serious functional impairment is high.52 There are over a dozen longitudinal epidemiological studies of child and adolescent mental health disorders<sup>53</sup> unequivocally pointing to homotypic and some heterotypic continuities (e.g. adolescent conduct disorder linked with adult depression) between childhood, adolescent and adult disorders. As we shall see, even in disorders where continuities are most obvious (e.g. depression, ADHD and antisocial behaviour) there are heterogeneities in the category with some sub-types of a disorder manifesting strong continuity (e.g. early onset conduct problems with callous-unemotional (C-U) traits).5

Some clarification of this complexity has been achieved by separating out common and unique features of mental disorders using latent class modelling.<sup>54</sup> Caspi and colleagues<sup>55</sup> found that individual differences in proneness to persistent psychopathology can be explained in this way using longitudinal data. They showed that diagnostic categories load on to externalising, internalising or thought disorder spectra and that the correlation between these is represented by a higher order general psychopathology dimension which they name 'p' (drawing structural and conceptual parallels to the general intelligence factor, 'g'). Risk factors that most childhood mental disorders have in common are likely to link to this higher order overarching indicator of persistence and impairment. An example of this may be maltreatment.

#### Maltreatment

Maltreatment increases the likelihood of most types of mental illness<sup>56</sup> and worsens their course. <sup>57,58</sup> Childhood maltreatment doubles the likelihood that the disease will become chronic and thus relates directly to persistence. <sup>59</sup> The methylation of certain genes could mediate the long-term effects of childhood adversity. <sup>60</sup> There may be inherited differences located in specific genes that amplify or attenuate the effects of adversity and determine who is or is not resilient. <sup>61</sup> This may explain why the presence of a family history of psychiatric illness more than quadruples the effect of maltreatment or maternal negativity on the likelihood of developing borderline symptomatology. <sup>62</sup>

#### Resilience

Resilience is the flipside of such vulnerability to environmental influence. From a developmental point of view, successful adaptation despite disturbances that threaten the functioning viability or development of any system is of the greatest interest.<sup>63</sup> Sapienza helpfully lists the most widely reported correlates of resilience in young people (with implicated adaptive systems)<sup>64</sup>:

- 1) Positive relationships with caring adults (attachment);
- Effective caregiving and parenting (attachment; family);
- 3) Intelligence and problem-solving skills (learning and thinking systems; nervous system);
- 4) Self-regulation skills (executive function systems);
- 5) Perceived efficacy and control (mastery motivation; reward systems);
- 6) Achievement motivation (mastery motivation; reward systems);
- 7) Positive friends or romantic partners (attachment; peer and family systems);
- 8) Faith, hope, spirituality (religion; cultural systems);
- Beliefs that life has meaning (religion, cultural systems);
- 10) Effective teachers and schools (education system).

Racial and ethnic identity may be added as a further promotive factor or asset.<sup>65,66</sup>

Attempts at enhancing resilience are central to the positive psychology movement.<sup>67</sup> The outcomes of the resilience programme based on this theory have been mixed<sup>68</sup> and the UK implementation was not successful.<sup>69</sup> Research on resilience has delivered different interventions that move away from deficit-focused models and towards strength-based or competence-based models; for example, prevention-science models that focus on enhancing competence or wellness,<sup>70</sup> the strength-based school counselling movement,<sup>71-73</sup> and the 'Looking After Children' child welfare movement.<sup>74</sup> These interventions have elements in common: they have positive goals, include positive influences and outcomes in models of change, use measures that include positive indicators or resources, consider multiple systems and are multidisciplinary.<sup>75</sup>

#### Diagnostic conditions\*

#### **Schizophrenia**

Perhaps the most effective adoption of a developmental perspective has been in the management of schizophrenia. It has been noted for some time that later schizophrenia was associated with schizotypy in late adolescence<sup>76</sup> and even earlier with minor psychotic-like features<sup>77</sup> (although psychotic-like experiences have a relatively high prevalence in children aged 9–11<sup>78</sup>). This is consistent with the assumption of early neurodevelopmental impairment.<sup>79</sup> Based on these developmental assumptions, numerous teams providing early intervention for psychosis have been established,<sup>80</sup> with several studies offering evidence of a possible delay or even prevention of transition to psychosis.<sup>81</sup> This has not yet, however, been effectively translated into routine practice: most teams provide early treatment of first episode psychosis rather than genuine prevention.

The potential for effective psychosocial intervention is signalled by the prevalence discrepancy between the elevated rate of diagnosis of Afro-Caribbean people living in the UK compared with those living in the Caribbean region, <sup>82</sup> mediated by separation and social disadvantage. <sup>83</sup> Further, childhood trauma, in particular peer victimisation and bullying, as well as parental neglect and abuse, has a clear cumulative effect, increasing the risk for psychosis. <sup>84</sup> There is increasing evidence for a potentially effective psychotherapeutic complement and even an alternative to medication. <sup>85</sup>

#### **Depression**

In prepubescent children depression is uncommon (1-2%).<sup>86</sup> It increases to 10–17% by early adulthood.<sup>87</sup> The female preponderance characteristic is established in the mid-teens where 12-month prevalence is 4-5%.<sup>88</sup> Comorbidity is pervasive in depressed young children, raising questions of whether at this age it is not a global syndrome of emotional and behavioural dysregulation.<sup>89</sup> Follow-ups of pre-school samples provide evidence of continued risk for depression into school years.<sup>90</sup> Although evidence is sparse, prediction to adult depression from childhood depression is limited.<sup>91</sup>

Depression and anxiety predict each other<sup>92</sup> and both predict alcohol use disorders in adulthood, with self-medication as the intervening mechanism.<sup>93</sup> Of the psychosocial risks, chronic stressors affecting relationships appear to have the greatest impact.<sup>88</sup> Heritability estimates are lower for childhood than for adolescent depression<sup>94</sup> and the importance of social (family) adversity, neglect and peer relationships is greater for the younger group.<sup>95</sup> There is evidence of epigenetic alterations in gene expression from post-mortem brain tissue studies of depressed individuals.<sup>96</sup>

NB Throughout this section, statistics refer to various populations, rather than UK or England populations. For details, please see the referenced papers.

#### **Attention Deficit Hyperactivity Disorder (ADHD)**

The traditional distinction between hyperactivity, impulsivity and inattention does not withstand developmental scrutiny. Findings suggest that attention deficits increase while hyperactivity decreases with age<sup>97</sup> although the two are significantly associated with each other<sup>98</sup> and institutional upbringing increases the severity of both.<sup>99</sup> By school age, almost three-quarters of those with ADHD have at least one other diagnosis.<sup>100</sup> About one-third of children with ADHD show remission by adulthood, while the rest continue to have either the full syndrome (about 15%) or significant symptoms.<sup>101</sup> Medium-to-high effect sizes are reported when adult outcomes, such as academic achievement, job performance, relationship and marital problems, and early pregnancies, have been aggregated across a dozen or so studies.<sup>102</sup>

Genetic influences are powerful in ADHD, with a heritability estimate of 0.76<sup>103</sup> which may (in part) account for early social risk from maternal smoking, low birth weight, prematurity and maternal stress.<sup>5</sup> In pre-school, severity of ADHD is the most likely predictor of its persistence but parenting practices predict behavioural adjustment.<sup>104</sup> In later childhood and adolescence comorbidity with conduct problems emerges as an important predictor of persistence.<sup>105</sup>

#### **Oppositional and conduct problems**

Conduct problems are the most common mental health disorders in childhood and adolescence. 106 The risk factors include impulsiveness, low IQ, low school achievement, poor parental supervision, punitive and erratic parental discipline. cold parental attitude, child physical abuse, parental conflict, disrupted families and dissocial parents, large family size, low family income, antisocial peers, schools with high delinquency rates, high crime neighbourhoods<sup>107</sup> but many of these may be markers for other risk mechanisms. 108 Early disruptive behaviour problems tend to improve without assistance over the first 10 years of life. 109 Those who do not desist (about 5%) are most likely to have poor family environments and hostile, ineffective and inconsistent parenting.<sup>110</sup> Family adversity is highest in those with a life-course persistent path<sup>111</sup> but even those whose onset is in adolescence show both individual and family adversity.<sup>112</sup>

A substantial minority (between 10% and 40% depending on the sample) of childhood onset conduct disorder is associated with C-U features reminiscent of adult psychopathy<sup>113</sup> which predicts severe and persistent antisocial behaviour.<sup>114</sup> An extensive literature on these children identified low temperamental fear<sup>115</sup> and deficits in attending to salient emotional social cues,<sup>116</sup> both of which may undermine normal attachment processes (triggered by fear) and the development of moral emotions.<sup>117</sup> As these children show minimal aversive experience when being punished, ignore emotional cues of the suffering of others<sup>118</sup> and cannot be engaged in emotional discussions,<sup>119</sup> therapeutic efforts could be considered a challenge. Nevertheless, there is evidence that being exposed to nurturing and warm

parenting can protect children from developing C-U traits even if they manifest fearless temperaments. 120,121

#### Anxiety

Anxiety tends to decline from kindergarten to the end of primary school and remains high in only about 14% of children. 122,123 While adolescents tend to experience low anxiety levels, a sub-group of about 5% show transient elevated anxiety levels specific to this period 124 associated with fear of bullying, increased homework and peer relationships in relation to transfer to secondary school. 125 A small sub-group of girls, however, experience a progressive increase in anxiety starting in mid-adolescence and which might reflect underlying biological vulnerabilities 126 and seems most strongly associated with parental anxiety or parental depression.

#### **Substance abuse**

Binge drinking is common (39% in European 15–16 year olds),<sup>127</sup> the age of onset is decreasing<sup>128</sup> and illicit drug use is replacing alcohol.<sup>129</sup> The increase in risky behaviour has been attributed to the rapid development of the socioemotional system hypothesised to lead to dopaminergic activity and sensation-seeking before the cognitive control system responsible for self-regulation is fully developed.<sup>130</sup> The adolescent brain is sensitive to alcohol and other substance-related degeneration during periods of neuromaturation.<sup>131</sup> Cannabis in adolescence may elevate the risk of schizophreniform disorders.<sup>132</sup>

A positive relationship with one's parents (feeling accepted and parental monitoring) is associated with reduced future alcohol consumption.<sup>133</sup> Conversely, the effects of peers on risk-taking behaviours are strongest in early-to-mid adolescence and peer acceptance strongly activates brain regions underpinning the reward system.<sup>134</sup> There are risk factors but there is no prodrome for substance use disorder.<sup>135</sup> Substance misuse is highly correlated with internalising and externalising mental disorders both as a consequence and as a cause, perhaps to some extent part of the same aetiology.<sup>136</sup>

While risk-taking and substance use are normative, those with childhood disruptiveness, impulsivity and sensation-seeking (the endophenotype) are at greater risk of substance-related problems in later life. There is evidence to suggest that gambling and gross internet dependency may share risk factors with substance use disorders.<sup>137</sup>

#### Conclusion

We now understand a great deal about developmental paths to disorder, including increasingly their biology and susceptibility to change. A set of clinical actions and universal, indicated, targeted preventive interventions supporting positive child development have the potential to enhance the life chances of patients and families for decades to come. All evidence points to the treatment context being the family and the interventions needing to be genuinely intergenerational.<sup>138</sup>

Childhood is a time of great opportunity but also of substantial risk. The economic case for early intervention is well rehearsed and by now generally accepted across political parties and professional disciplines. 139 Up until now the magnitude of the impact of both child and adultfocused interventions has been limited, certainly when brought to scale. 140-142 Developmental neuroscience is ready to guide early childhood intervention by targeting specific neurobiological systems through computer-based brain training and ecologically valid promotions in real-world settings (e.g. homes, classrooms and Sure Start centres) of the practice of specific behavioural skills hypothesised to relate to the neural systems of interest. 143,144 The cutting edge of prevention is two-generation programmes simultaneously tackling the impact of adversity on parent and child. 145,146 For example, a joint approach to parent and offspring who share problems of self-regulation (e.g. inhibitory control) linked to substance abuse<sup>147</sup> offers an opportunity to design interventions on neurocognitive functions and behavioural competencies in children, parents and family systems. 138

The future lies in genuinely vertically integrated (bi-generational) programmes that build on the revolution in life science knowledge, both biological and psychosocial, which simultaneously address the problems of the parents and the child to help them break out from what is likely to be an almost Lamarckian epigenetic trap that otherwise dictates that not just history, but also biology, will repeat itself.

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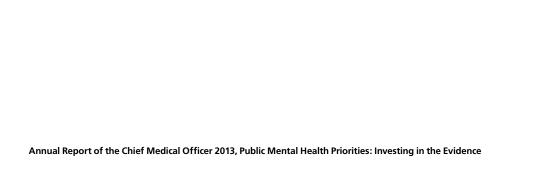
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## Section 3

## Mental health across the life course



## Chapter 6

# Life course: children and young people's mental health

#### **Chapter authors**

Tamsin Ford<sup>1,2,3</sup>, Oana Mitrofan<sup>4</sup>, Miranda Wolpert<sup>5,6</sup>

- 1 Professor of Child and Adolescent Psychiatry, Institute of Health Research, University of Exeter Medical School
- 2 Unpaid Director, Child Outcomes Research Consortium
- 3 Honorary Consultant, Devon Partnership Trust
- 4 Academic Clinical Lecturer, Institute of Health Research, University of Exeter Medical School
- 5 Director, Evidence Based Practice Unit, University College London and Anna Freud Centre
- 6 Director, Child Outcomes Research Consortium

#### Key statistics

- In 1999, 10% of British 5-15 year olds had a psychiatric disorder (according to standardised diagnostic assessment), but only 25% of these accessed mental health services over the next three years.<sup>1,2</sup>
- Bullying worsens childhood³ and adult mental health⁴ and is experienced by between a third and half of British school children and young people.<sup>5,6</sup>
- Nearly half the children and young people with a clinically diagnosable disorder also had a disorder when surveyed 3 years later.<sup>1,7</sup>
- More than 75% of adults who access mental health services had a diagnosable disorder in prior to the age of 18.7
- Extensive disinvestment in specialist child and adolescent mental health service (CAMHS) provision in England since 2011 has amounted to 25% cuts in some areas.<sup>8,9</sup>
- There has been an increase in average waiting times to 15 weeks for CAMHS since 2011.8
- Only 40% of CAMHS involved in national benchmarking report being able to provide crisis access for young people.8
- Some 91% of paediatric departments reported increased presentations of young people with self-harm in 2013 compared with 2012, which was compounded by the lack of urgent or crisis access.<sup>8,10</sup>
- Service providers report increased complexity and severity of problems among children and young people seeking services since 2011.<sup>10,11</sup>
- Some 81% of teams involved in peer review in 2013 report using National Institute of Health and Care Excellence (NICE) recommended practice, up from 50% in 2008.<sup>11,12</sup>

#### Overview

This chapter builds on the developmental psychopathology perspective presented in Chapter 5 of this report, 'Developmental psychopathology: a perspective'. It was included in response to the Chief Medical Officer's (CMO's) concerns about children's mental health and their access to services, which were raised in the mental health chapter of the CMO's report 'Annual Report of the Chief Medical Officer 2012 Our Children Deserve Better: Prevention Pays' (summarised in Box 1).<sup>13</sup> The CMO's concerns were discussed by the Health Select Committee convened in February 2014.

This chapter will provide a brief summary of the prevalence and impact of problems related to mental health in childhood (under 18 years of age), and will consider the impact of digital culture, cyber-bullying and self-harm. It will also explore issues around service provision, including access, quality and effectiveness.

#### Availability of data

We lack nationally collated current data on the present extent of mental health problems and service provision. 10,14,15 The last national community survey is a decade old, and both national surveys excluded children under 5 years old.<sup>1,2</sup> Prospective surveillance can provide policy and practicerelevant data on rare conditions and events that collectively can be costly and difficult to manage, 16 but such surveillance struggles for funding. The Child and Adolescent Psychiatry Surveillance System and the British Paediatric Surveillance Unit use monthly cards to collect data from consultant child and adolescent psychiatrists/paediatricians, sometimes jointly, about a range of rare disorders (early-onset bipolar disorder), conditions (conversion disorder) and events; a study on the cost-effectiveness of different types of services for young people with anorexia will commence data collection in the autumn. 16,17 National collation of a minimum dataset for CAMHS is delayed, and the last CAMHS mapping data around service provision was collected in 2009, which predates the widespread adoption of social media.<sup>18</sup> This chapter draws on published research and audits, but more up-to-date, comprehensive national statistics are urgently needed.

#### Introduction

The chapter focuses on the mental health and wellbeing of children (primary school age and below) and young people (secondary school age/adolescents) below the age of 18 years. The language used to describe poor mental health reflects that in the literature quoted. The term psychiatric disorder is applied when structured diagnostic assessments have been used to assign diagnoses according to the various versions of the International Classification of Diseases or the Diagnostic and Statistical Manual of Mental Disorders. The term difficulties is applied when studies have used standardised questionnaires to measure the number of symptoms or problems, and impairing psychological distress is applied to those scoring above established cut-off points on these questionnaires. Impairment refers to the distress, impact on the child or young person's ability function and the burden to others caused by the child or young person's difficulties.

The prevalence of psychiatric disorder among 5-15 year olds was 10% in two large national population-based surveys. 1,2 Children under the age of 5 were excluded from both these surveys. The prevalence of disorder in this group has been overlooked internationally, but the limited literature suggests that the prevalence is similar to that found in school-aged children. 19 Combined data from these surveys revealed that half the 5-15 year olds with at least one psychiatric disorder also had a psychiatric disorder 3 years later. 20 Parental psychological distress and burden, neurodevelopmental disorder and intellectual disability predicted 'persistence', which suggests that effective support for these non-mental health difficulties might promote children's recovery.

5-15 year olds with psychiatric disorder were three times as likely to have psychiatric disorder in adulthood.<sup>21,22</sup> Half those with psychiatric disorder at age 26 had a psychiatric disorder before the age of 15, three-quarters by age 18, and even more among mental health service users.<sup>7</sup> Conduct disorder predicted all adult psychiatric disorders including psychosis,<sup>7</sup> so effective intervention to reduce childhood behavioural difficulties may be a particularly potent lever to improve both child and adult mental health.

Impairing psychological distress and psychiatric disorder are associated with exclusion from school, <sup>23</sup> occupational failure, intimate relationship breakdown and criminality. <sup>24</sup> Choices about education, occupation and childbearing during the teenage years can have profound impacts on subsequent life chances, while behaviours that predicate future health – such as diet, exercise, sexual activity and psychoactive substance use – develop during adolescence. <sup>25</sup> Given known links between economic uncertainty and mental health, <sup>26</sup> as well as the association of childhood psychiatric disorder with both social disadvantage and parental psychological distress, <sup>27,28</sup> the levels of mental health difficulties in children and young people require urgent reassessment, as austerity may disproportionately impact on their mental health and wellbeing. <sup>26</sup>

Psychopathology among British 15–16 year olds increased in the latter quarter of the last century,<sup>24</sup> with no change between 1999 and 2004.<sup>29</sup> 5-15 year olds with psychiatric disorder do not form a discrete group when psychological distress is measured using symptom scores, although the proportion with disorder is closely associated with the mean (average) score.<sup>30</sup> Many children are struggling, while effective interventions could potentially improve functioning across the whole population as well as among those with disorder, although this requires empirical testing.<sup>31</sup>

Furthermore, the substantial societal costs of antisocial behaviour are not confined to those with conduct disorder, but are evident among the more numerous children with lower levels of behavioural difficulty.<sup>32</sup> Effective early intervention for these less severely affected children may lead to substantial mental health gains as well as cost savings across a number of agencies. Sadly, child and adolescent psychiatrists report the recent 'wholesale removal of Early Intervention Services across the country', which often included such 'indicated prevention' as a key facet of their work.<sup>10</sup>

#### Key issues

#### **Digital culture**

We are raising a generation of 'digital natives' who differ from previous generations in the way they communicate, seek information, interact and entertain themselves.<sup>33,34</sup> Electronic media has some positive influences, such as improved spatial perception, faster information processing and the provision of useful tools to motivate learning, improve psychosocial adjustment and enhance academic performance.<sup>35–37</sup> There are, however, widespread concerns about potential negative effects, which include increased physiological arousal, decreased attention, hyperactivity, aggression, antisocial or fearful behaviour, social isolation and excessive use or 'technological addiction', 38-42 but evidence is sparse and contradictory. Watching television for more than 3 hours per day by age 5 predicted a small increase in behavioural problems at age 7, but playing electronic games did not, while neither predicted emotional symptoms, hyperactivity/ inattention, peer relationship problems or prosocial behaviour.<sup>43</sup> More direct harm may arise from websites that normalise unhealthy behaviours as lifestyle choices, such as anorexia and self-harm. 44-46 A review of literature on the harms experienced by child users of online and mobile technologies from 2008 to 2013 suggests that definitions and measures influence reported prevalence rates, but the latter were not increasing<sup>47</sup> in contrast to popular opinion, possibly because of greater awareness and safety training.

Evidence that exposure to media violence prompts increased aggression is conflicting.<sup>48</sup> Some meta-analyses suggest small to moderate associations between seeing violence in passive media (e.g. television) and interactive media (e.g. video games) with aggression in both children and adults, 49,50 while another suggests that exposure only influences younger children and is short-lived.<sup>51</sup> A systematic review of exposure to media violence among children with impairing psychological distress found insufficient, contradictory and methodologically flawed evidence, 52 despite previous reports that these children may be more susceptible.53 A schoolbased intervention to reduce 'screen time' in American primary school children significantly decreased peer-rated aggressive behaviour but had no effect according to parental or observer reports.<sup>54</sup> Restricting children and young people's access to electronic games by using age and violent content labels may paradoxically increase their attractiveness; the socalled 'forbidden-fruit effect'.55

#### Box 6.1 Selected text from Annual Report of the Chief Medical Officer 2012 Our Children Deserve Better: Prevention Pays<sup>13</sup>

### Mental health problems in children and young people are common...

- A total of 1 in 10 children and young people aged 5–15 years had a clinically diagnosable mental disorder...
- Self-harm is common, particularly in adolescence and those with a mental disorder.
- The prevalence of impairing psychological distress rose between 1974 and 1999, but data on current trends in the UK are not available.

## Mental health problems are often persistent and have costly and wide-ranging impacts on life chances ...

- Some 50% of adult mental illness (excluding dementia) starts before age 15 and 75% by age 18.
- Children and young people with poor mental health are more likely to have poor educational attainment and employment prospects, social relationship difficulties, physical ill health and substance misuse problems and to become involved in offending.
- Mental health problems in childhood and adolescence in the UK result in increased costs of between £11,030 and £59,130 per child annually.

## Social disadvantage and adversity increase the risk of developing mental health problems

Children and young people from the poorest households are three times more likely to have a mental health problem than those growing up in better-off homes.

### There are effective, evidence-based clinical intervention and prevention strategies

- Evidence-based practice may reduce costs by up to 35% and duration of treatment by up to 43%.
- Early intervention may reduce the risk of later disorder and save money.

## Access to evidence-based interventions is problematic because of:

- Geographical variation in access to services and in implementation of evidence-based interventions
- Recent reductions in funding in CAMHS, particularly in local authority expenditure
- Long waiting lists and extremely high thresholds for referral
- Lack of integration between agencies.

## There are many areas where knowledge is insufficient to guide practice and there is a need for:

- clarity about diagnostic criteria for some mental health disorders and assessment
- epidemiological data on rates and profiles of childhood mental health problems, particularly for under-5s and children and young people from minority ethnic groups
- data on interventions currently offered to children, and their outcomes
- more and better evaluations of interventions
- innovative methods of service delivery
- more data on adverse outcomes (including those from psychological therapies).

## Action is needed at multiple levels – from societal to individual – to improve the mental health of England's children and young people to address the issues above, including:

- implementation of evidence-based and outcomebased approaches to intervention
- integration across all parts of healthcare systems
- investment that is proportionate to the associated health burden
- addressing inequalities in mental health promotion and prevention
- measures to support parents, particularly with parenting skills
- enhancing the role of schools in relation to mental health
- better mental health informatics to support evidencebased commissioning
- addressing workforce and training issues and shortfalls in resources in CAMHS.

#### **Bullying and cyber-bullying**

Bullying, or repeated exposure to the negative actions of others where an imbalance of power is present, is reported by 34-46% of English school children in recent surveys.<sup>5,6</sup> 'Cyber-bullying' through digital media<sup>56</sup> may now be the most common type of bullying.<sup>57</sup> Between 8% and 34% of young people in the UK have been cyber-bullied, according to figures published between 2008 and 2011, with girls twice as likely to be victims of persistent cyber-bullying. 48 Cyberbullying lacks time or space boundaries, so young people have no respite from their persecution.58 A single episode can be re-posted and forwarded multiple times. 59 The use of technology provides anonymity and allows for more frequent sexual content and greater cruelty compared with face-to-face bullying. 60-62 Cyber-bullying can be particularly difficult to tackle because of non-existent or nascent legal frameworks for intervention, logistical difficulties in tracking the originators of anonymous messages and the proliferation of photograph-sharing applications.<sup>58</sup> Some interventions to prevent or reduce cyber-bullying among young people have been developed, but none have been rigorously tested.63

Bullying may precipitate or aggravate depression, anxiety, psychosomatic symptoms, eating difficulties and self-harm, and is associated with suicide.<sup>3,64–70</sup> A dose-response relationship exists, which means that children who are exposed to frequent, persistent bullying have higher rates of psychiatric disorder.<sup>71</sup> Exposure to bullying is also associated with elevated rates of anxiety, depression and self-harm in adulthood.<sup>4,72</sup> People are often bullied because of a perceived difference, which is sometimes mental health problems.<sup>73</sup> In a study conducted at a community-based specialist CAMHS in 2007, nearly two-thirds of CAMHS users reported being bullied. Of these bullied CAMHS users, 63% identified bullying as an important reason for their CAMHS attendance.<sup>74</sup>

Classroom management and social structure are associated with substantial differences in the level of reported bullying,75 which suggests that bullying in schools is an important and tractable public health issue.76 'Whole-school-based' interventions are more effective than curriculum-based interventions or behavioural and social skills training.<sup>77</sup> The Olweus Bullying Prevention Program, the most researched bullying prevention/reduction programme, demonstrated average reductions of 20% in student-reported experience of bullying or being bullied over 2 years in several largescale evaluations involving more than 40,000 students.<sup>78</sup> Reductions of up to 70% were reported in some schools. Similarly, the KiVa bullying intervention program resulted in a reduction of approximately 20% in both bullying perpetration and victimisation among participating schools.79 Other strategies include educating young children about bullying (e.g. the classroom conflict resolution model, daily check-ins, peace circles and peace journals) and encouraging children to approach an adult or a friend for help.80 The high prevalence of bullying reported in recent UK surveys suggests that we are currently failing to respond to it effectively. Research from the mid-1990s also suggested that the prevalence of bullying

in UK schools was at the higher end of the range detected across European schools and lacked the clear decline with age seen in data from other countries.<sup>78</sup> Between 18% and 20% of English school children reported being bullied 'sometimes or more often' compared with a range of 4% to 20% across Europe.<sup>81</sup>

#### Suicide and self-harm

Suicide and self-harm throughout the lifespan is covered in depth in Chapter 15 of this report, 'Suicide and self-harm'. Suicide in children is rare; there were six and nine recorded suicides among 10-14 year olds in England during 2011 and 2012 respectively.82,83 Suicide verdicts are not returned for children under 10 years of age, and statistics on 10–14 year olds do not include deaths with an undetermined cause (seven in 2011 and 10 in 2012) that may relate to neglect or abuse as well as self-inflicted injury in this age group; self-inflicted injury is assumed for indeterminate deaths in over-15s.82,83 Suicide is one of the leading causes of death in adolescence.84 A pilot study for the confidential inquiry into maternal and child health suggests that most of those who completed suicide had not had prior mental health services contact, but there were also some failures to follow up those who were referred to CAMHS but failed to attend.85

Child psychiatrists and paediatricians report<sup>10</sup> an alarming rise in self-harm presentations to paediatric departments, particularly among girls, which in some areas exceeds 50% and is compounded by a lack of urgent or crisis access.<sup>8</sup> Self-harm is associated with impairing psychological distress, completed suicide and increased service use, but we lack effective evidence based interventions to reduce it, other than active treatment of any underlying disorder or difficulties, if present.<sup>86</sup> Evidence suggests that less than half of young people attend mental health follow-up, which can be increased by the use of therapeutic assessment.<sup>87</sup>

#### Access to services

Provision of CAMHS in England is dispersed across a range of organisations, including NHS mental health trusts and children's trusts, independent providers, social care, education and the voluntary sector. CAMHS provision ranges from mental health promotion, training and consultation to non-mental health practitioners and direct clinical care which involves outpatient appointments, outreach services, emergency out-of-hours assessment and inpatient admissions. CAMHS are provided across a wide range of locations from primary care to community settings (including coffee bars and youth centres) and schools, as well as secondary healthcare. There is an increasing use of technology to support training of others and choice of services, as well as to support direct therapeutic work, although to date there has not been much rigorous evaluation of these innovative approaches.88

CAMHS have traditionally adopted a wide variety of service models with little standardisation, but in recent years quality networks and learning collaborations have supported greater consensus about common standards and metrics to measure performance and impact (see Box 6.2). Over the last 2 years these collaborations have joined forces with the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme to create a core model across key elements of outpatient and community provision (see Box 6.3).

Historically, CAMHS have been underfunded, with few services meeting the minimum staffing level recommended per head of population<sup>89</sup> and most services lacking IT or electronic care records that are fit for purpose. Although there was some growth in services during 2008–2011, with targeted ring-fenced area funds, since 2011 there has been a reduction in funding and consequent reduction in service provision.<sup>8,9</sup> Waiting times have increased since 2011; maximum waiting times for specialist CAMHS were on average 15 weeks in 2012/13. The 3-week median wait for urgent access is of particular concern, as is the lack of rapid access through crisis pathways reported by 60% of responding providers.<sup>8</sup>

Schools are increasingly seen as a key focus for future work for mental health promotion and intervention. Primary schools that undertook embedded mental health support as part of a randomised controlled trial under the national Targeted Mental Health in Schools initiative were found to have improved outcomes for pupils with behavioural difficulties.<sup>87</sup> Acceptability was high among children and professionals.<sup>90–92</sup> The lack of ring-fenced money to support such work in schools means that the continued development of such initiatives requires direct commissioning by schools or other sources.

Meanwhile, CAMHS providers report increased demand in terms of the number and complexity of referrals combined with cuts in CAMHS budgets, which are exacerbated by parallel cuts in social care and education that significantly impede joint agency working.9,10 Only 25% of children with psychiatric disorder accessed specialist mental health services over 3 years; 43% reported no mental health-related service contact at all, though many reported contact with other services (41% teachers, 29% primary care, 25% specialist educational services, 14% paediatrics and 14% social care).25 The costs to the education system of additional contacts related to mental health were enormous. School (£799.2 million) and specialist educational service (£508.8 million) costs greatly exceeded the costs of mental healthrelated contacts to other public sector services (£162.8 million to health and welfare combined; 2007/08 prices).93 Service contact, however, does not necessarily indicate effective intervention, and marked inter-individual variation in both the levels of service use and the costs observed across all types of service imply inequality in the way that services responded to children's mental health needs and system-wide inefficiencies in resource allocation.94 Some factors predicting service contact, such as parental psychological distress and reading difficulties, underline the need for joint agency working to support children's mental health.

#### Box 6.2 Useful web resources

#### Information about mental health, CAMHS and interventions:

- www.minded.org.uk
- www.mycamhschoices.org
- www.youthwellbeingdirectory.co.uk
- www.youthinmind.org
- www.rcpsych.ac.uk/healthadvice/ parentsandyouthinfo.aspx

#### Information about quality and training:

- www.youthaccess.org.uk
- www.rcpsych.ac.uk/quality/quality,accreditationaudit/ communitycamhs.aspx
   www.rcpsych.ac.uk/quality/quality,accreditationaudit/ qnic1.aspx
- www.corc.uk.net
- www.cypiapt.org/children-and-young-peoplesproject.php?accesscheck=%2Findex.php

Children and young people with more severe difficulties were more likely to access services than those with milder difficulties. 95–100 Service use was also related to contact with key referrers, such as primary healthcare and teachers, 97 and the recognition of difficulties in the young person and/or key adults such as parents and teachers. 97,99,101–108 Children and young people with disruptive behaviour were more likely to access services than those with emotional difficulties whose problems may be less evident to others. 107,109 Training for key professionals could improve detection, and may be particularly important for emotional disorders, provided that services have the capacity to respond.

A lack of inpatient beds has led to increasing numbers of inappropriate placements of young people on adult wards and at impractical distances from home. 10,14,110 Two case series suggest that intensive treatment teams can safely intervene in the community with young people to reduce impairment, although evidence of reduced number and/or duration of admissions is anecdotal and no cost-effectiveness studies have been published to date. 111,112

While all upper-tier local authorities but one have a health-based place of safety for the assessment of people detained under section 136 of the Mental Health Act, 35% do not accept young people under the age of 16 and 17% are restricted to over-18s. <sup>113</sup> This is of particular concern, as child and adolescent psychiatrists report increasing use of section 136 to detain young people. <sup>10</sup> Where no health-based place of safety is available, they are taken to police cells or local government offices, which are deemed unsuitable for adults. <sup>10,14,114</sup>

## Transition from CAMHS to adult mental health services

A 2010 study found that transition from CAMHS to adult mental health services was poorly planned and executed, with poor flow of information, low rates of joint working and poor continuity of care.<sup>110</sup> Failure to refer because of perceived high thresholds in adult services was much more common than failure of adult services to accept referrals. Young people often face multiple simultaneous transitions between health, education and social care systems, which should be safe, understanding and tailored to the young person's needs.<sup>14,115</sup>

Some areas are developing 0–25 services, such as the youth service in Norfolk. The rationale is to avoid the transition at the age of 18, as young people aged from mid-teens to early 20s have the highest prevalence<sup>22</sup> of psychiatric disorder and poorest access to services.<sup>114</sup> There is particularly poor service access for 18–25 year olds, who may fall below the criteria for adult services and are not able to access CAMHS after the age of 17 or 18, especially among those with emotional disorders and neurodevelopmental difficulties such as attention deficit hyperactivity disorder and autism spectrum conditions.<sup>110</sup> The extension of service provision up to 25 years would represent huge additional demands without additional funding, and areas that opt for services for those aged 13–25 years risk introducing a different, additional transition point.<sup>10</sup>

#### **Quality and effectiveness of services**

An increasing number of evidence based interventions are available for a range of childhood psychiatric disorders. There remains a consistent gap between the impact of psychological therapies within efficacy studies and routine practice, The which may be partially explained by the failure to adopt evidence based interventions and to implement them with fidelity, But may also relate to the need to develop an evidence based practice that relates to the complexity of cases seen within services.

Chapter 10 of Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays<sup>13</sup> highlighted in detail the high cost-to-benefit ratio of evidence based interventions in children under 5 years of age, 120 which is briefly summarised below. There is strong, reliable evidence on the effectiveness and cost-effectiveness of pre-school language curricula to enhance school readiness and early literacy, and parenting programmes to improve children's behaviour, as well as parent-child therapy and home visiting programmes to improve parent-child relationships. 120 Intensive family and child support can address both carerchild relationships and behaviour.120 There is evidence of efficacy for the active detection and treatment of postnatal depression, 121 as well as programmes that focus on improving the quality of the parent-infant relationship during the first year of life;122,123 cost-effectiveness data are not yet available. These interventions have been delivered in the UK across a variety of sectors, including children's centres and CAMHS, but are a major component of the early intervention services that are being widely withdrawn.<sup>10,14</sup>

There is encouraging uptake and implementation of evidence based practice across CAMHS, which increased to 81% in 2013 from 50% in 2008 among teams participating within a peer-review network. There is also evidence of increased use of routine outcome monitoring supporting the development of practice-based evidence, with more than 50% of services part of the Child Outcomes Research Consortium (CORC) committed to routinely collecting outcome data to inform and refine clinical interventions (see Box 6.3). Involvement in such collaborations can increase implementation, and the use of these approaches can reduce drop-out and increase services' effectiveness.

The CYP IAPT programme (see Box 6.4) is a national initiative that aims to enhance the implementation of NICE-recommended evidence based interventions while also advancing the use of routine outcome monitoring and encouraging best practice in user participation and service development. This approach, which involves the collection of child and parent/carer-reported measures of psychological distress and satisfaction, has uptake even beyond those directly involved, with 70% of services involved in national benchmarking reporting commitment to CYP IAPT principles.8 A CYP IAPT accreditation group has now formed that combines key organisations around a common set of standards and aims to continue to inform the greater standardisation of high-quality care. Fidelity to the evidence based intervention manuals<sup>126–128</sup> is an important influence on effectiveness, as is the therapeutic alliance developed between the practitioner and the child and their family. 129-131 The importance of access to sufficient training and supervision should not be underestimated. 132,133

While there is variation across services, on average parents reported greater improvement in child difficulties following CAMHS attendance with teams that submitted data to CORC than would be expected by chance or natural remission. Reported satisfaction with services also varied across services but is mostly high. Across services collecting satisfaction data as part of CORC, 77% of children and 83% of parents said they had definitely received good help, but only 60% and 63% respectively thought their appointments were definitely convenient. 136

#### **Box 6.3 Child Outcomes Research Consortium (CORC)**

#### Issue

- Lack of access to feedback from children, young people and families accessing specialist mental health provision about the impact on their lives and their experience of care means that service providers and commissioners cannot effectively develop or improve services in the light of such data. Challenges to implementation of routine feedback include:
- lack of agreement as to appropriate measures
- inappropriate IT and service infrastructure to support data collection, collation and analysis
- clinician disengagement with the collection and use of such data.

#### **Action**

- The Child Outcomes Research Consortium (CORC) is a voluntary grassroots learning collaboration of child mental health providers committed to finding the best ways to collect, collate and make use of patient-reported outcome measures (PROMS) and patient-reported experience measures (PREMS) to help to improve the quality of the services they provide.
- The collaboration has agreed a common set of measures, a common dataset that has become the basis of the national dataset, and a common protocol for collection of measures.
- A small central team help members to address IT challenges and use centrally aggregated anonymised information from members' services to provide benchmarking comparison and bespoke analysis of data.
- CORC provides training to frontline clinicians, supervisors and others in how to implement routine outcome measurement and analysis in such a way as to support collaborative working and shared decision making between both clinicians and service users. CORC also supports a particular structured approach to the consideration of performance data between service providers and commissioners.<sup>134</sup>
- CORC has grown from an informal network of four services to an international learning collaboration consisting of 70 services across the UK and with members in Scandinavia and Australia. CORC now holds the most comprehensive data from CAMHS across the UK over the last decade. As a learning collaboration, members are able to shape research and discuss key aspects to improve service delivery.

#### **Evaluation**

- Data on impact and experience of service use have been analysed for more than 63,000 episodes of care from more than 60 services and used to inform decision making and commissioning.
- Independent audits have found that involvement in the collaboration has increased implementation of outcome measurement from 30% to 60%.
- Members report that benefits of being part of the collaboration include support in data collection and training, and IT advice and support.
- CORC members report that their benchmarking reports have been key elements in their commissioning discussions.

## Box 6.4 Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme

#### Issue

■ CAMHS have traditionally been fragmented, with a lack of standardised elements of best practice, and may be of variable quality. There has been variable uptake of latest evidence based practice (in particular NICE guidelines) and the use of routine outcome monitoring to guide therapy and improve collaborative working between client and therapist, to demonstrate outcomes and goals achieved, and to support development of practice-based evidence and best practice in relation to participation of children and young people.

#### **Action**

CYP IAPT supports service transformation by participating CAMHS (NHS, voluntary sector and local authorities) working in partnership with higher education institutions (HEIs). The programme is achieving 'transformation of CAMHS' by investing in training in evidence based therapies and infrastructure improvement, and requires adherence to an agreed monitoring protocol and to improving participation. The programme has developed a set of standards and practices with national accrediting and quality improvement bodies working together on CYP IAPT.

Services receive training and support in:

- NICE-approved approaches for key problems, including parent training for parents of 3–8 year olds with behavioural problems, cognitive behavioural therapy (CBT) and interpersonal therapy for adolescents (IPT-A) with depression, and systemic family practice (SFP) for adolescents with depression, conduct problems and eating disorders and who self-harm
- use of session-by-session outcome monitoring (drawing on the learning from CORC and others). This includes:
- using routine outcomes monitoring to help clients to monitor and understand how their treatment is progressing and to guide the therapist and supervisor
- empowering young people to take control of their care, establish treatment goals, choose treatment approaches and take opportunities to improve their own health
- service development strategies and improvement initiatives (drawing on learning from the quality improvement networks of the Royal College of Psychiatry, the Choice and Partnership Approach (CAPA) and others), and also working closely with service user groups.

The initiative commenced in 2011, and will directly involve services covering 60% of the 0–19 population by 2015.

#### **Evaluation**

During the life of the initiative, the reported uptake of evidence based practice interventions among CAMHS teams as part of a peer-review network has risen to 81% (from 50% in 2008).

Some 70% of services involved in a national benchmarking exercise in 2013 reported adhering to the principles of CYP IAPT even if they were not directly part of the project.

Activity and outcome data are being collected from all participating services. These are currently being used to assess and improve data quality before substantive analysis of impact can be undertaken.

Figure 6.1 Example of text cloud created using free text comments from the CHI-ESQ

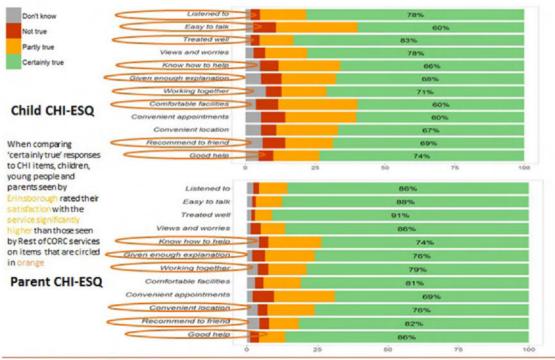
Children & Parents' comment on the service:





The above text cloud has been created using the free text comments from the CHI-ESQ. The size of the text represents the frequency of each word in the sample, with the most common words being largest. For further information: http://wordle.net (Your CHI-ESQ comments are not saved or stored online)

Figure 6.2 Example of experience domains from a CORC dashboard





\*The Rest of CORC comparison comprises of CHI-ESQ measures from children, young people and parents seen by CORC+member services during the specified reporting period (1st April to 31st December 2013)

# Conclusion

Psychiatric disorders among children and young people are common<sup>1,2</sup> and persistent, <sup>18,19</sup> and may increase in these austere times given the greater pressures on families and shrinking support available to them. 10,14 Given the costs to all public sector services and the impact on future health and mental health, child mental health should be a high policy priority. We desperately need high-quality data on which to further develop services and to base the next generation of child mental health research programmes. There is a need for rigorous evaluations of different service models as well as more randomised trials of interventions and their implementation with fidelity into routine clinical practice. Improved co-ordination across children's services and between child and adult mental health services is essential. Childhood behavioural problems, bullying and selfharm stand out as particular issues that warrant improved intervention and future research, while children, young people and their families should be actively involved in service development and improvement.

Despite the many challenges outlined above, there are three particular areas of positive development. Greater collaboration and consistency across CAMHS are coalescing around shared standards of practice that combine implementation of evidence based practice with a commitment to develop the practice-based evidence base, service user involvement and collaborative working. This work needs to be actively supported and encouraged. The potential of schools as direct funders of interventions brings opportunities to develop preventive work, but it is essential that chosen programmes have an evidence base and/or are rigorously evaluated. The innovative use of new technology brings the possibility of increased access to training for professionals and to information and support for young people and their families, although it is again essential that such initiatives are supported by rigorous evaluation of effectiveness and safety.

# Authors' suggestions for policy

- Government should commission a regular prevalence survey for the collection of prevalence data for children and young people's mental health, which includes information on minority ethnic groups, 0–5s, school-based variables such as bullying and teacher—pupil relationships, and the impact of social media.
- Local authorities should prioritise against further disinvestment in children and young people's mental health services.
- Commissioners should urgently implement the recommendations of the NHS England Tier 4 rapid review (http://www.england.nhs.uk/wp-content/ uploads/2014/07/camhs-tier-4-rep.pdf) so that young people are no longer placed in inappropriate settings.
- The Department of Health, Public Health England and NHS England should work collaboratively to identify opportunities for service provision to improve the access to support for young people who require ongoing support after they become too old for CAMHS.
- Improving children and young people's mental health in England involves co-ordinated action from multiple agencies on multiple levels.
- The investment in mental health services and prevention for children and young people should be proportionate to the associated health burden.
- Commissioning should recognise the potential of schools to promote resilience among children and young people and as settings in which to deliver child mental health interventions.
- Conduct disorder predicts all types of adult mental illness; as it is the most common mental health disorder among children and young people, effective intervention could have large benefits for children, adults and society.
- Healthcare providers and commissioners should ensure that services provide evidence based interventions with fidelity, sufficient training and supervision, as well as the routine use of outcome monitoring.
- Government policies should actively address inequalities; prevent mental ill health among children, young people and adults; and promote recovery.
- Government policies should actively support parents and parenting, with expected benefits to both child and adult mental health, with particular attention paid to effective intervention for parental mental illness.
- Healthcare systems require improved access to technology to support needs-based commissioning and routine outcome monitoring.
- The effective commissioning and delivery of CAMHS require ongoing work to redress workforce and training issues and the shortfall in resources.

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# Chapter 7

# Life course: adults' mental health

# **Chapter authors**

Stephen Stansfeld<sup>1,2</sup>, Sally McManus<sup>3</sup>, Kamaldeep Bhui<sup>4</sup>, Peter Jones<sup>5,6</sup>

- 1 Professor of Psychiatry, Centre for Psychiatry, Barts and the London School of Medicine and Dentistry, Queen Mary University of London
- 2 Honorary Consultant Psychiatrist, East London NHS Foundation Trust
- 3 Research Director, NatCen Social Research
- 4 Professor of Cultural Psychiatry and Epidemiology, Wolfson Institute of Preventive Medicine, Queen Mary University of London, East London NHS Foundation Trust
- 5 Professor of Psychiatry, University of Cambridge
- 6 Director, National Institute for Health Research, Collaboration for Leadership in Applied Health Research and Care East of England

# Key statistics

- Most adults with mental illness experience their first episode of mental illness before the age of 16.1
- Adversity in childhood increases the likelihood of mental illness in adulthood: e.g. non-consensual intercourse before the age of 16 increases the odds of psychosis in adulthood 10-fold.<sup>2</sup>
- People with extensive experience of physical and sexual abuse both as a child and as an adult are 15 times more likely to have multiple mental disorders than people without such experiences.<sup>3</sup>
- In England, about one person in six (17.6%) aged 16–64 had a common mental disorder (such as anxiety or depression) in the past week. This draws on England's best available data on prevalence of mental disorders, the 2007 Adult Psychiatric Morbidity Survey.<sup>4</sup>
- Common mental disorders are more likely in women (21.5%) than men (13.5%) of working age. This pattern is also true of eating disorders.<sup>5</sup>
- However, drug dependence (5.4% of men; 2.8% of women), alcohol dependence (9.3% of men; 3.6% of women) and problem gambling (0.8% of men; 0.2% of women) are more common in men than women.<sup>6</sup>
- Common mental disorders tend to be highest in midlife, among particular black and minority ethnic (BME) groups,<sup>7</sup> and in those living in low-income households.<sup>8</sup>
- Psychotic disorders also arise more commonly in BME communities; e.g. schizophrenia is five times more common in black communities. However, this is not confined to schizophrenia and involves a range of ethnic groups.<sup>9</sup>
- People living in cold homes<sup>10</sup> and those who are in debt<sup>11</sup> have higher odds of mental illness, even after controlling for low income.
- Common mental disorders are twice as frequent in carers who are caring more than 20 hours a week than in the general population.<sup>12</sup>
- A quarter (24%) of people with common mental disorders were in receipt of some kind of mental health medication or therapy (when interviewed in 2007). Some 76% were not.

# Overview

Many aspects of people's lives are woven together and are linked with mental illness in adulthood. These include:

- adversity in childhood (such as experience of child sexual abuse and presence of emotional and conduct disorders in childhood)
- demographics (being female; in midlife; belonging to particular ethnic groups; and lacking educational qualifications)

- socio-economic context (living in social housing; on a low income; in debt; poor housing conditions; and lacking employment or in stressful working conditions)
- social relationships (separation or divorce; living as a one-person family unit or as a lone parent; and experience of violence or abuse)
- health, disability and health behaviours (low predicted IQ; impaired functioning; physical health conditions; nicotine, alcohol and illicit drug consumption).

This chapter uses an epidemiological perspective to examine each of these groups of factors in turn, except for health, disability and health behaviours which are examined in Chapter 13 of this report, 'Physical health and mental illness'.

While Chapter 6 of this report, 'Life course: children and young people's mental health' focuses on childhood and adolescence and Chapter 8, 'Life course: older adults' mental health' focuses on older age, here the focus is broadly on the 'working age population'. We do seek to highlight where there are differences in rates of mental disorder and risk factors between young adults and those in midlife; however, the issues are often similar for both groups. Throughout the chapter we place a strong emphasis on variations in mental illness, and seek to identify the variations in risk and protective factors that might explain these differences.

# The evidence base

The primary source of data on trends, prevalence and predictors of mental illness in England is the ongoing Psychiatric Morbidity Survey (PMS) series, funded by the Department of Health since the early 1990s. Increasingly, administrative data produced through treatment and service use contact are being linked and can provide a powerful resource for epidemiological research. However, general population survey data indicated that only a quarter of people interviewed with clinically significant symptoms of anxiety or depression were also receiving medication or talking therapy at the time. Treatment and service use data therefore paint a partial – and potentially biased – picture of mental illness in England.

The Adult Psychiatric Morbidity Survey (APMS) is based on a large, national and random sample of the general population living in private households. It was first conducted in 1993, and repeated using comparable methods in 2000 and 2007. Another round of data collection is currently taking place, with findings available in 2016. Interviews are conducted over the course of a full calendar year with people aged 16 and over using face-to-face interviewing, with laptop self-completion for the most sensitive questions. The questionnaire is detailed, covering both a range of different diagnostic assessment tools and the key risk and protective factors for mental health. Further clinical interviews are carried out with a sub-sample of respondents. Data from APMS 2007 are drawn on extensively in this chapter.

Britain's psychiatric morbidity survey programme has included surveys focused on specific sub-groups, such as people living in prisons,<sup>13,14</sup> who are homeless,<sup>15</sup> with caring responsibilities<sup>16</sup> or from minority ethnic groups.<sup>17</sup> However, these surveys are now all more than a decade old. The lack of recent population-based data on the mental health of sub-groups such as these represents a critical gap in the epidemiological evidence base on mental disorder in England.

Another key gap is the lack of general population longitudinal surveys that include good diagnostic assessments of mental health. Longitudinal data of this kind would help analysts to further unpack causal direction in some of the associations discussed in this chapter; for example, to understand whether being in debt explains subsequent onset of mental illness, or whether being mentally ill increases the likelihood of getting into debt.

The Mental Health, Dementia and Neurology Intelligence Networks have been launched, which include tools that bring together a range of publicly available data modelled to give a prediction of mental illness rates by clinical commissioning groups and local authority areas. This is as an important step forward in parity and public transparency of data for public mental health.

# The evidence base: impact of adverse events, vulnerability and mental illness in childhood persist into adulthood

Just as the seeds of a long and healthy life are sown in childhood, so too are the origins of much mental illness. Preventive public mental health interventions should begin in childhood, and efforts to understand and alleviate mental disorders of adulthood must take into account a life course perspective.

Early adversities and childhood maltreatment, including sexual, emotional and physical abuse, neglect and lack of care through poor parenting, impact on mental health in children and increase the risk of affective and anxiety disorders in midlife.<sup>18,19</sup> This is partly explained by adversity triggering adolescent onset disorders which persist into adulthood in one form or another, as well as by continuity of vulnerability induced by exposure to early adversity in combination with genetic effects. Low birth weight, the presence of neurological deficits and low measured IQ predict adulthood depression and less common conditions such as psychotic illness. All these factors are associated with increased exposure to psychosocial stressors and fewer personal resources with which to cope. Childhood stressors with lifelong impact on mental health also include bullying, running away from home and institutional care.<sup>20,21</sup> The consequences of bullying on mental health may be tackled through schools-based programmes, while parental mental

illness and poor parenting may be best addressed in familyoriented programmes.

# The evidence base: some demographic groups experience more mental illness than others, but the nature of these variations depends on the type of mental disorder

Variations in rates of mental disorder across the adult population are due to numerous factors, including genetic predisposition and differential exposure to risk. In this chapter we are taking a health inequalities perspective, as this highlights opportunities for public mental health policy intervention. Health inequalities exist for mental illness, just as they do for physical illness.<sup>9</sup> However, the nature and direction of these inequalities vary by type of mental disorder.

# Life stages and types of mental illness

Different mental disorders exhibit different patterns of association with age. Some, such as attention-deficit hyperactivity disorder (ADHD), have childhood onset as part of their definition. Conduct disorder in childhood is a requirement for a diagnosis of antisocial personality disorder in adulthood. Autism and personality disorders are defined as life-long, and so should not be associated with age in adulthood. In practice, many do show an association with age, because people learn to manage their condition and the prevalence of the disorder is changing between birth cohorts, or due to 'healthy survivor' effects (that is, people without the condition tend to live longer than those with it). In highincome countries, mental illness tends to be more common among people under the age of 65 than among those who are older. This pattern of association with age varies with country and birth cohort, and by type of mental disorder. In England, common mental disorders (CMD) such as depression and anxiety peak in midlife, and are lowest around postretirement.22,23

# Age of onset

Most mental disorders have their onset in childhood, adolescence or young adult life, with onset much rarer in middle age or later. Data from the World Mental Health Surveys suggest that half of all lifetime mental disorders start by the mid-teens and three-quarters by the mid-twenties. Later onsets tend to be secondary to other problems, and severe disorders are nearly always preceded by less severe disorders (see Table 7.1<sup>23</sup>). The average age of onset of non-affective psychoses such as schizophrenia is between the late teens and mid-twenties.

Table 7.1 Ages at onset for five categories of mental health disorder

		Age at which % of projected lifetime risk attained, years <sup>b</sup>		
	Projected lifetime risk % (s.e.)	25%	50%	75%
Anxiety disorders	31.5 (1.1)	6	11	21
Mood disorders	28.0 (0.8)	18	30	43
Impulse control disorders	25.4 (1.1)	7	11	15
Substance use disorders	16.3 (0.6)	18	20	27
Any disorder	50.8 (1.2)	7	14	24

a proportion of whole population that will have experienced disorder by age 75 years

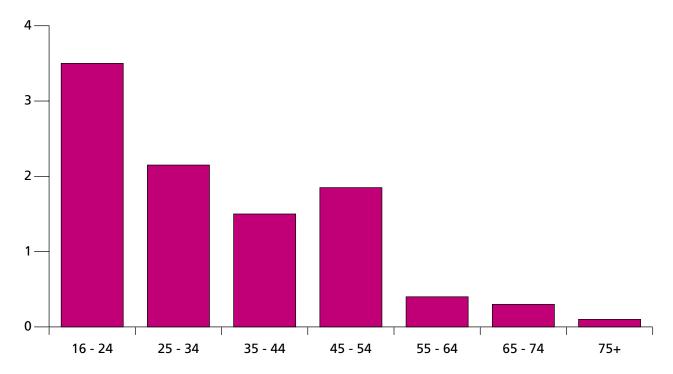
# Young people

That so much mental illness begins in childhood and the teenage years suggests a reappraisal of adult conditions in order to understand and prevent them. The transition from child to adult is lengthy, taking up to two decades. There is no abrupt change as might be suggested by the way health and social care services are organised. The brain embarks on an epic phase of development around puberty that is incomplete until the late 20s. This is accompanied by profound cognitive, psychological and social changes for the individual and their interaction with peers, family and society, including leaving school, entering employment or further

training, developing intimacy, personal relationships and self-confidence, and finding a place within the community. The combination of these changes can contribute to the development of mental illness and substance dependence among those young adults who are predisposed to mental illness.

Anxiety, depression, substance misuse and psychosis, in particular, are mental disorders that present special problems at this life stage. The first episode of psychosis tends to be experienced during this epoch. It is the most persistently disabling condition, especially for young adults, in spite of

Figure 7.1 Positive screens for eating disorder decline sharply with age



Source: Adult Psychiatric Morbidity Survey 2007

b data for standardised age-at-onset distributions of DSM-IV diagnoses derived from the World Health Organization Composite International Diagnostic Interview with projected lifetime risk at age 75 years; adapted from Kessler et al. where data on specific diagnoses and details of the sample are available

recovery of function by some individuals in mid to late life. Eating disorders are most prevalent in early adulthood, as well as several impulse control and substance disorders (see Figure 7.1). In Britain, alcohol and drug misuse and dependence peak among women in their twenties and men in their thirties. The lower prevalence in later life may be because people recover from their addiction, become homeless or institutionalised and are thus excluded from age prevalence surveys, or because they die. Young people are more likely to experience violent trauma (due to road accidents, violent crime or, in a minority, experience of active armed service), and as a result may be more likely to develop post-traumatic stress disorder (PTSD).

### Midlife

In Britain, the prevalence of mental illness peaks among people in their middle years (forties and fifties) as problems persisting from youth accumulate with new onsets in others; prevalence is lowest among those in their sixties and seventies (see Figure 7.2). This pattern of association between age and mental illness is a neat reversal of the widely reported U-curve in positive mental wellbeing, lowest in midlife, which has been identified.<sup>24,25</sup> Explanations proposed for the excess of neurotic symptoms at this life stage include the realisation of limited achievement while people are still aspirational; the squeeze resulting from a combination of caring responsibilities for children and for ailing parents; work-related stress; and the menopause. Some stressful life events that can be damaging to mental health, such as marital breakdown, also become more likely at this stage of life.

# Older age

There is a stage, around the time of transition to retirement, when rates of mental illness are particularly low. However, there is also evidence that rates increase again somewhat in late older age. These issues are explored in Chapter 8 of this report.

# Gender

Common mental disorders such as anxiety and depression are more likely in women (21.5%) than men (13.5%), with both major and minor depressive disorders more common in women than men.<sup>26</sup> This pattern also holds true for conditions such as borderline personality disorder and eating disorders.<sup>5</sup>

However, other mental disorders, such as antisocial personality disorder (0.6% of men; 0.1% of women); drug dependence (5.4% of men; 2.8% of women); alcohol dependence (9.3% of men; 3.6% of women) and problem gambling (0.8% of men; 0.2% of women)<sup>27</sup> are much more common in men than women. One widely accepted view has been that women are more likely to internalise their emotions, which can bring on withdrawal and loneliness, whereas men are more likely to externalise them, becoming aggressive and impulsive.

Overall, in any given year, women appear to experience higher rates of psychological disorder than men.<sup>27</sup> Psychosocial and environmental factors seem to be more important in accounting for these differences than biological or genetic factors.<sup>28</sup> Women seem more sensitive to adverse

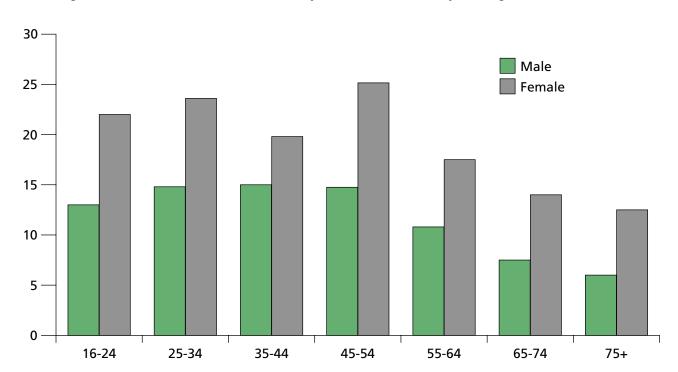
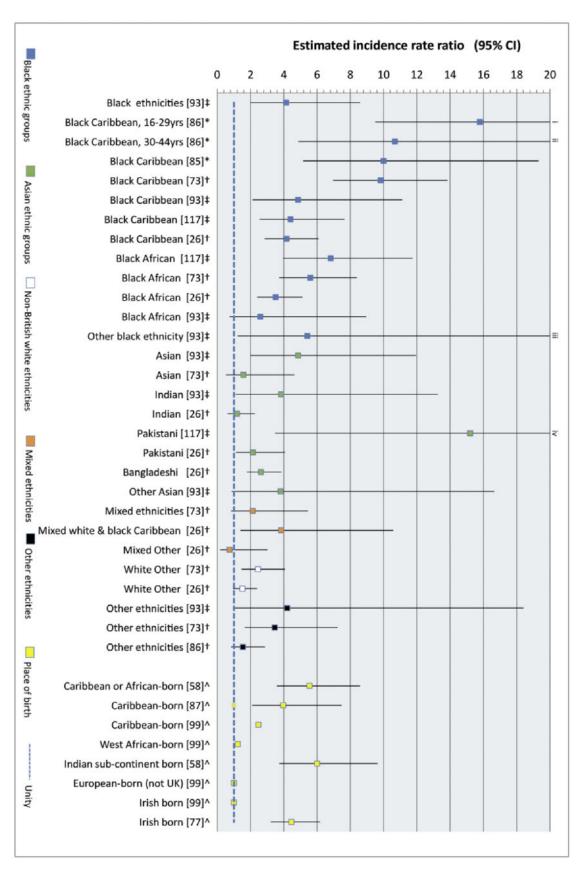


Figure 7.2 In England, common mental disorder is most likely in midlife and least likely in old age

Source: Adult Psychiatric Morbidity Survey 2007

Figure 7.3 Reported incidence rate ratios of schizophrenia by ethnic group and country of birth, England, 1950-2009



Point estimates are coloured by broad ethnic group. Incidence rate ratios (IRR) are in descending order for specific ethnic groups. Baselines are represented by blue dashed line: †white British; ‡white group; \*Non-black Caribbean; ^UK-born Source Kirkbride et al., 2009

experiences in childhood, as well as being at greater risk of sexual abuse, which may have long-term mental health consequences.<sup>29</sup> In adulthood, women do not consistently experience more traumatic life events than men but the reaction to life events (particularly salient events related to children and relationships) may have more meaning, and subsequently more impact, for women than men.<sup>30</sup>

Also it is plausible that women experience higher levels of stress because of the competing demands of multiple social roles: they are expected to function as carer, homemaker and breadwinner and are also more likely than men to be judged on the basis of their appearance.<sup>27</sup> Women have particular risk of a psychotic episode postpartum, particularly where they have a history of bipolar disorder.<sup>31</sup> The impact of mental disorders in the perinatal period is especially important due to the effect not only on the mother, but also on the pregnancy and subsequently on the child.<sup>32</sup>

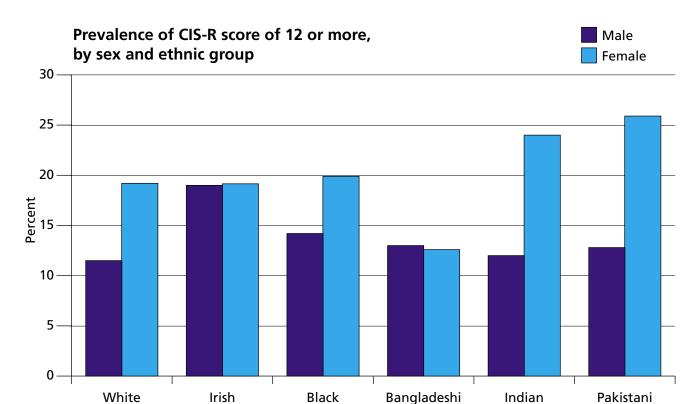
Freeman and Freeman (2013)<sup>27</sup> note that the elevated overall rate of mental disorder among women emerges as a consistent picture across different countries, and has received surprisingly little research attention. This variation in rate has implications for the design and delivery of treatment, as well as for understanding psychiatric epidemiology.

# **Ethnicity**

There are disparities by ethnic group in the incidence rate of a number of mental illnesses, with several conditions being more common in black and minority ethnic (BME) groups (see Figure 7.3). This is important because public and mental health service provision needs to take account of the needs of particular communities, including recent migrants.

Psychotic disorders, such as schizophrenia, were reported as arising more commonly in the black Caribbean community since the mid-20th century. Many reasons for this have been proposed but, even after confounding factors are accounted for, the findings remain robust as studies have become more sophisticated. Moreover, excess incidence rates of other serious mental illnesses, such as depressive psychosis and bipolar disorder, have been found in BME groups too. Kirkbride and colleagues (2009) undertook a systematic review of all relevant studies in England over a 60-year period and examined the role of ethnicity, migration and place of birth, and upbringing. Incidence rates of most psychotic disorders were elevated in several ethnic minority groups compared with the white (British) population (see Figure 7.4).

For example, the incidence rate of schizophrenia was over five times more common in the black Caribbean communities studied; nearly five times in the black African population; and doubled in South Asian groups in England. Such differences appear to be partly driven by socio-economic characteristics but unique factors related to being from a BME group remain important in understanding this health inequality and present a target for policy and intervention. Moreover, the responses of mental health services to people from BME communities who develop and live with psychotic illnesses as long-term conditions have been found wanting in the past. There



Caribbean

Figure 7.4 Prevalence of common mental disorders by gender and ethnic group

Source EMPIRIC (Sproston and Nazroo, 2002)

are now additional challenges as the population becomes culturally more diverse.

Many of the risk factors for CMD and psychotic illnesses in ethnic and migrant groups are related to social adversity and material deprivation and traumatic and adverse life events. Some of these are more common in specific ethnic groups and migrant populations. The EMPIRIC survey, funded by the Department of Health, is probably the largest comparing specific ethnic groups.<sup>7</sup>

Compared with white counterparts, the prevalence of CMD was higher among Irish (RR = 2.09, 95% CI 1.16–2.95, p = 0.02) and Pakistani (RR 2.38, 95% CI 1.25–3.53, p = 0.02) men aged 35–54 years; and this was despite adjusting for differences in socio-economic status.<sup>7</sup> Current socio-economic status did not explain the findings, although Das Munshi et al. (2013) suggest that material deprivation in early life may explain higher rates in second generation Irish people.<sup>33</sup> In EMPIRIC, higher rates of CMD were also observed among Indian and Pakistani women aged 55–74 years compared with white women of similar age. The prevalence of CMD among Bangladeshi women was lower than among white women, although this was restricted to those not interviewed in English. There were no differences in rates between black Caribbean and white samples.

Protective factors such as social capital are difficult to measure but studies suggest this is helpful and may mitigate risks,<sup>34</sup> and social support is also influential.<sup>35</sup> Discrimination and racism are also risk factors for CMD and psychosis.<sup>36,37,38</sup> Intimate partner violence may also have differential impacts and prevalence across ethnic and racial groups.<sup>39</sup> Studies of refugees and victims of trauma indicate that there is a higher risk of depression and PTSD among them, and this is related to traumatic experiences and human rights violations.<sup>40,41,42</sup>

Suicide and self-harm (a strong predictor of suicide) are commonly reported to be very prevalent in young South Asian women; however, recent data suggest that young black Caribbean and black African women and older South Asian women are also at greater risk. 43,44

Alongside the higher rates of CMD among Indian and Pakistani women and Irish and Pakistani men evident in the EMPIRIC data, alcohol dependence emerges as particularly common among white men, and black men and women have high rates of PTSD (even after controlling for differential exposure to trauma).

The combined impact of these health inequalities should be reflected in local needs assessments and commissioning decisions. In mental health these have hitherto been made on the basis of national norms that do not take into account the particular characteristics of local communities. Open-source models such as <a href="https://www.psymaptic.org">www.psymaptic.org</a> reveal a more granular picture of need, in this case for early intervention for psychosis in young people (see Figure 7.5). Accounting for demographic variation supports more sophisticated commissioning decisions, resource allocation and service provision to meet local needs.

# The evidence base: current economic context may be having an impact on the mental health of the workingage population

After 15 years of decline, since the onset of recession the suicide rate in England has shown signs of an upturn again. This is not surprising; this section of the chapter discusses how much of the epidemiological data that we have indicate that socio-economic context may be a key factor in poor mental health. The best available general population data on mental illness in England, the 2007 Adult Psychiatric Morbidity Survey (APMS), were collected before the recession began to bite. The next survey in the series, with data available in 2016, will provide an indication of the impact of recession on rates of mental illness in England.

### Income

Generally, people living in low income households are more likely to experience mental illness.<sup>46</sup> For example, people in England living in households with the lowest income are more than three times more likely to have mental illness.

Countries with high levels of income inequality, such as the UK, have higher rates of homicide, suicide and illness.<sup>47, a</sup> Some authors have disputed this, reporting that these findings are artefacts of data selection.<sup>48</sup> Major depressive disorders are more frequent and persistent in less socially advantaged groups. CMD are less clearly socially patterned but in general are associated with social disadvantage. Assessments of social deprivation at the neighbourhood level act as a useful proxy measure for individual level deprivation and can be useful for planning need for services.

### **Debt**

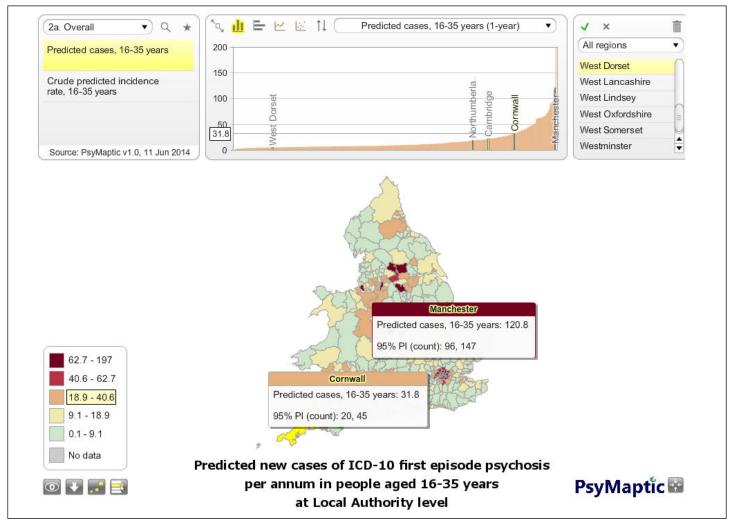
There are social inequalities in general and mental health.<sup>9,49</sup> Both low income and debt are associated with mental illness, but the effect of income appears to be mediated largely by debt.<sup>8,46</sup> This may be compounded by financial exclusion (the inability to access recognised financial services in an appropriate way).<sup>50</sup>

# Housing conditions and fuel poverty

People with CMD are also more likely to experience all aspects of fuel-related poverty.<sup>51</sup> Equally, not being able to heat the home in winter, having a combination of fuel and other debt, having mould and limiting fuel use because of cost all predict CMD.<sup>52</sup> Having a cold home, particularly the living room, contributes to social isolation and may be associated with stigma.<sup>8</sup> A quarter of people with a cold home reported reluctance to invite people home as a result

a The Chief Medical Officer notes that there is ongoing debate about this concept, despite face validity.

Figure 7.5 Example of Psymaptic image



Source Psymaptic (http://www.psymaptic.org/)

with potential limits on their social interactions. This may be more of an issue for older people.

# **Unemployment**

Unemployment is consistently related to higher rates of depression and anxiety<sup>53</sup> and suicide, with higher risk in countries with inadequate unemployment benefits.<sup>55</sup> Health and social factors may lead to unemployment but this explains only part of this association.<sup>56</sup> This is of major public health importance at a time of austerity, with many people facing unemployment, financial hardship and debt. Furthermore, during economic recession people with existing mental illness are more likely to be excluded from the labour market.<sup>57</sup> The loss of role and status, lack of financial resources and the disruption of social networks all contribute to the mental health effects of unemployment.58 This is especially an issue for younger people, often with few qualifications, who are unable to enter the labour market. Associations with poorer mental health are stronger in men than women except where women are the main household breadwinners. The negative impact on mental health may be greater when unemployment is an exceptional event and mitigated when peers are also unemployed. However,

in relation to the worldwide recession since 2008 there seems to be an increased risk of mental illness and suicide in Europe<sup>59</sup> and the USA.<sup>60</sup> This may be due to exposure to multiple disadvantage, severe financial constraints and little prospect of improvement. Mental health benefits, measured by screening questionnaires for depression and anxiety, have been found in longitudinal studies after re-employment.<sup>53,58</sup>

# **Adverse working conditions**

The quality of working conditions is related to mental health, the effect varying across countries. <sup>61</sup> Jobs with high levels of strain, effort–reward imbalance, and low social support from managers and colleagues are associated with increased risk of CMD. <sup>62</sup> Additionally, job insecurity, prevalent in today's labour market, is a risk factor for CMD. The accumulation of adverse working conditions increases the risk of CMD; the mental health of people in very low quality jobs is equivalent to those who are unemployed. <sup>63</sup> Recent research has identified the toxic effect of workplace bullying on mental health. <sup>64</sup> Those in occupations involving a lot of contact with the public (where there is a risk of violence or verbal abuse) have higher rates of CMD than those who are not. There may be interventions at the level of the organisation or workplace

such as training for managers and job redesign that could prevent the development of CMD. Greater wellbeing may also be related to greater productivity at work, increased commitment and staff retention as well as effects on health and longevity,<sup>65</sup> and more research is needed to investigate this

# The evidence base: social context and relationships are key to mental health

# **Social relationships**

The family is a key social setting which has implications for mental health, both positive and negative. Divorce and family break-up are becoming more common and may have implications for mental health. Consistently divorce has far-reaching effects on children's mental health through associations with the lack of care, neglect, emotional abuse and financial disadvantage that may sometimes result from relationship breakdown.66 Domestic violence is an important cause of CMD in women that could be alleviated through interventions in primary care. <sup>67</sup> On the other hand, emotional support from close relatives and friends has positive effects on wellbeing and buffers the effects of life events on depression. Negative aspects of close relationships can increase CMD rates; conversely, social support has been recognised as a crucial factor in conferring resilience to the effects of long-term stressors.<sup>68</sup> Social isolation is not only a risk factor for depression but also increases the risk of coronary disease and mortality probably through influences on blood pressure, and endocrine and immune responses. 69,70 Lone parenthood is associated with CMD in both men and women.71

Indirectly, government policies may influence the capacity to maintain personal relationships, through reduction of social inequalities, housing design that promotes rather than inhibits social contacts with neighbours, provision of local jobs, maternity and paternity leave, the ability to have flexible working hours and consideration of work–life balance. There is scope for new research to assess whether paternity leave, flexible working hours and work–life balance positively influence personal relationships and wellbeing. People with CMD are more likely to have experienced several stressful life events in the last 6 months, and to have smaller social networks.<sup>72</sup> These features are even more marked in prisoners, homeless people and informal carers than in the general population.<sup>8</sup>

# **Caring responsibilities**

Over 6 million people provide informal unpaid care in the UK, estimated to rise to 9 million by 2037.73,74 Caring for a relative with an illness or disability may make carers vulnerable to both physical<sup>75,76,77</sup> and mental illness,<sup>78,79,80</sup> including depression and anxiety.81,82,83 The caregiving role is associated with disturbed sleep,<sup>79,84</sup> immunological and endocrine dysfunction83,85 and elevated mortality.86 These negative health seguelae are frequently enduring, 87 although they may vary during the different phases of the illness and caregiving relationship.88 Reducing caregiver burden and improving carer wellbeing thus remains a major responsibility for government and public health bodies<sup>74,89</sup> especially as carers have been described as an 'invisible healthcare system'90 alongside the NHS. Primary stressors within caring that may lead to mental illness, directly relating to the caring role, include dealing with difficult behaviours and aggression from the care recipient, 91 or with difficult emotions. Secondary stressors that may also be implicated in mental illness include stressful life events, difficulties with finances and employment, 92 housing, 93 and restricted opportunities to engage in social and recreational activities.

# Interpersonal violence and abuse

Domestic violence is a major public health issue worldwide, 94 and may account for up to 7% of the overall burden of disease in women, largely as a result of its impact on mental illness. 97 A quarter of the English adult population have experience of violence and abuse in their lives. Violence and abuse are strongly associated with a wide range of mental disorders. 96,97 People with extensive experience of physical and sexual violence are five times more likely than those with little experience of violence to have a CMD. More than half of this group meet the threshold for a CMD. They are also 15 times more likely to have multiple (three or more) mental disorders. 3

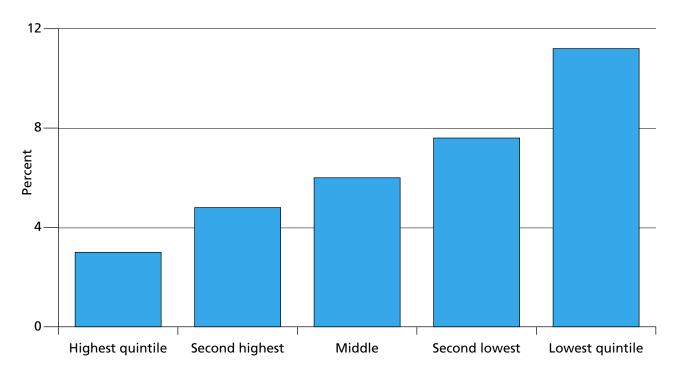


Figure 7.6 Percentage of individuals with at least one attempted suicide, rate by deprivation quintile, 2007

Equivalised household income. Base: 16 and over living in England, Adult Psychiatric Morbidity Survery 2007

# Suggestions for developing the evidence base

- Britain's psychiatric morbidity survey programme has included surveys of specific sub-groups, such as lookedafter children, the prison population, or people who are homeless, with caring responsibilities, or from particular ethnic groups. These surveys, however, are now more than a decade old. The lack of recent population-based data on the mental health of sub-groups such as these represents a critical gap in the epidemiological evidence base on mental disorder in England.
- The lack of longitudinal general population surveys that include good diagnostic assessments of a range of specific mental disorders is another key gap in the evidence base. Longitudinal data of this kind would help analysts to disentangle the causes and consequences of mental illness; for example, to understand to what extent being in debt explains subsequent mental illness, and to what extent being mentally ill increases people's chances of getting into debt.
- Linking survey and routine health data is one way to generate longitudinal data for some of the population. This approach addresses some of the limitations of relying solely on routine data, given that a minority of people with mental illness are in receipt of treatment.
- Modelled estimates where a national rate has been adjusted to reflect the socio-demographic profile of a local area – can be useful for planning local service provision. However, it is important to recognise that modelled

estimates may not correspond well with the actual rate in a particular area, and that such estimates are not meaningful in trend analysis or to evaluate the performance of an area.

# Overview of prevalence/trends

Based on APMS surveys 1993, 2000 and 2007:

- There was a significant increase in the proportion of the population aged 16 to 64 with a common mental disorder (CMD), such as depression or anxiety 'in the past week', from 15.5% in 1993 to 17.5% in 2000. No further increase was seen by 2007 (17.6%).
- The prevalence of alcohol dependence was 5.9% in 2007, having fallen somewhat in men since 2000. The prevalence of hazardous drinking among 16 to 74 year olds also fell, from 28.1% in 2000 to 25.5% in 2007. The prevalence of drug dependence was 3.4% in 2007, similar to 2000, but higher than in 1993.
- Suicidal thoughts at some point in a person's life are relatively common: in 2007 16.7% had thought about suicide, 5.6% reported attempting suicide and 4.9% had harmed themselves without suicidal intent. In England, the proportion of women reporting suicidal thoughts in the last year, and of people reporting self-harm, increased between 2000 and 2007.
- The overall prevalence of probable psychosis has remained stable at around 0.5%.
- Rates of personality disorder have remained stable. In 2007, antisocial personality disorder was present in 0.3% of adults (0.6% men, 0.1% women), mostly in the

- younger age groups, while borderline personality disorder was present in 0.4% of adults (0.3% men, 0.6% women).
- Psychiatric comorbidity was common, especially between antisocial personality disorder and drug dependence.
- A third of adults reported having experienced a life threatening traumatic event since the age of 16. Overall 3.0% of people screened positive for current PTSD (Post traumatic stress disorder) and rates declined with increasing age.
- 8.2% of adults screened positive for ADHD (attention deficit hyperactive disorder), as indicated by a score of four or more on a six item self-report scale; 2.3% reported five characteristics and 0.6% all six characteristics. Only a fifth of screen positive participants were receiving any psychiatric treatment.
- 6.4% of adults screened positive for an eating disorder, of whom a fifth were receiving treatment of some sort, and 1.6% of adults screened positive and reported that eating problems had a significant negative impact on their life.
- Two-thirds of adults had spent money on gambling in the last year, 3.2% met one or more of the criteria for problem gambling, 0.7% met three or more criteria, and 0.3% met the threshold of five or more criteria (taken to indicate pathological gambling). A quarter of the latter were receiving some kind of treatment for a mental or emotional problem.

# Conclusions

Across adult life there are many factors which increase risks for mental disorders that could be modified by policy interventions to reduce these risks. These include the effects of education, income, unemployment, debt, housing conditions, work and exposure to violence on mental health. This requires policy development across government.

Many of the most powerful impacts on mental health could be achieved through HM Treasury, the Department for Education, the Department for Work and Pensions and the Ministry of Justice, among others, alongside the Department of Health. It is also crucial that non-health departments are alert to the unintended negative consequences of their policies on mental health and how these can be avoided.

The Department of Health has an important role in providing accessible services for mental disorders, taking into account inequalities, and also in informing other areas of government about the mental health bonus or otherwise that may accrue to their policies. This also applies to local government where mental health surveys of specific local need can be helpful in targeting local resources efficiently. The mental health and wellbeing of adults is a key national resource that contributes to wealth as well as health and as such is the core business of government as a whole.

# Authors' suggestions for policy

- People with mental illness experience widespread social exclusion in education, employment and housing.
- Inequalities in the distribution of mental disorder in the population need to be taken fully into account in the allocation of resources to services, with refined algorithms.
- Evaluation of the impact of debt reduction intervention programmes is needed. The fact that, before the recession, a quarter of people with mental disorder were in debt has direct implications for effective clinical assessments and care planning, as well as for awareness in debt counselling agencies, utility companies and financial organisations.
- Good quality relationships are key to maintaining good mental health: access to relationship counselling and support plays a part in this.
- Routine enquiry about mental illness in people from highrisk groups, such as the unemployed, carers or migrants, needs to become part of clinical practice for opportunistic screening. Testing the effectiveness of this requires new research.
- While insulating homes is a priority given the impact of fuel poverty and living in a cold home on mental health, this must include proper ventilation if an increase in the physical and mental health conditions associated with mould is to be avoided.
- Now that problem gambling is defined as an addiction in the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition) and given its parallels to alcohol and drug dependence, problem gambling should be considered under the rubric of public health.

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# Chapter 8

# Life course: older adults' mental health

# **Chapter author**

Robert Stewart<sup>1,2</sup>

- 1 Professor of Psychiatric Epidemiology and Clinical Informatics, King's College London
- 2 Consultant Psychiatrist, South London and Maudsley NHS Foundation Trust

# Significant contributors

Alistair Burns<sup>1</sup>, Ahmed Hankir<sup>2,3</sup>, David Jolley<sup>4,5</sup>, James Warner<sup>6,7</sup>, David Challis<sup>8,9</sup>

- 1 Vice Dean (Clinical Affairs), Faculty of Medical and Human Sciences at the Institute of Brain, Behaviour and Mental Health, University of Manchester
- 2 National Institute for Health Research Academic Clinical Fellow in Later Life Psychiatry, University of Manchester
- 3 Participant, Harvard Medical School Global Clinical Scholar Research Training Program
- 4 Honorary Reader Psychiatry, Personal Social Services Research Unit, University of Manchester
- 5 Visiting Consultant Psychiatrist, Gnosall Memory Clinic, Stafford
- 6 Consultant/Clinical Director in Older Adults Psychiatry, Central and North West London NHS Foundation Trust
- 7 Honorary Reader in Psychiatry, Imperial College London
- 8 Director, Personal Social Services Unit, University of Manchester
- 9 Associate Director, National Institute for Health Research School for Social Care Research

# Key statistics

- Of people who use specialist mental health services, 34% are aged 65 and over,<sup>1</sup> yet only 16% of the general population are in this age bracket.
- Mental disorders in older people reduce quality of life, increase use of health and social care facilities<sup>2-4</sup> and are associated with a range of adverse outcomes when cooccurring with physical disorders.<sup>5-7</sup>
- 6% of people aged 65 and over live in care (94% of people aged 65 and over live in private households<sup>8</sup>). This 6% in care have a very high prevalence of dementia, depression and other mental disorders,<sup>9</sup> often in combination.
- Around 10–20% of people aged 65 and over in the community have depression,<sup>10</sup> as do 20–30% of those in care homes or on general hospital wards.<sup>11,12</sup>
- Depression responds to treatment similarly in older adults as it does in younger adults;<sup>13,14</sup> however, it remains poorly detected in primary care.<sup>15-17</sup>
- Some 20% of men and 10% of women aged 65 and over are drinking alcohol in harmful quantities. These data represent increases of 60% and 100% over the past 20 years.<sup>18</sup>
- Around 10% of nursing home residents have psychotic symptoms such as delusions and hallucinations,<sup>19</sup> and schizophrenia-like disorders occur for the first time in around 20 in 100,000 people aged 65 and over per year.<sup>20</sup>
- Standardised mortality ratios in people with hospitalised bipolar disorder aged 65 and over rose from 1.1 to 1.8 between 1999 and 2006; standardised mortality ratios for people aged 65 and over with hospitalised schizophrenia rose from 1.3 to 2.0 over the same period.<sup>21</sup>
- Over 60% of people aged 65 and over in acute hospital wards have a significant mental disorder, often unrecognised<sup>12,22</sup> and untreated; 20% of older people in medical wards have delirium.<sup>12,23</sup> Treatment of psychiatric morbidity reduces length of stay and care costs.<sup>24</sup>
- Mental health services for older people are underfunded. Achieving parity in service provision for adults aged 55-74 with those aged 35–54 would require a 24% increase in NHS mental health spending.<sup>25</sup>

# Overview

'Older age', although lacking a clear definition, represents an important period of life in which health and social care needs rise substantially and in which multiple mental and physical health problems are common and interacting, often compounded by social isolation. This chapter focuses on depression, psychosis and substance use disorders. However, although dementia and delirium are not specifically covered, they present an important context within which other mental disorders manifest. Mental disorders in older age have been substantially under-represented in policy discussions, falling between the focus of 'mental health' on working-age adults and that of 'older people' on dementia.

The key messages of this chapter are:

- that service provision should not be separated by mental disorder diagnosis, such as between dementia and other diagnoses, because these are too often overlapping
- that service specialisation by setting has often been successful (e.g. general hospital liaison) and might be developed further, for instance to care homes
- that collaboration between physical and mental health services should be encouraged in commissioning, as should that between health and social care
- that 'ageless' services present potentially serious longterm threats to mental health care for older adults, not only through immediate withdrawal of specialist service provision, but also through longer-term loss of specialist training. Such a radical change in provision should therefore be evaluated and demonstrated to represent an improvement before it is allowed to proceed further.

# Introduction and parameters

'Older age' generally encompasses two broad transitions:

- the predominantly social transition from working life to retirement not only capturing a constellation of potential life changes, e.g. in a person's perceived role, daily routine, income level and social environment, but also reflecting a time when patterns and lifestyles are set up which may have important longer-term implications, e.g. financial planning, patterns of family and social relationships, choice of housing, etc.
- the potential transitions of later 'old age', which include the accumulation of health conditions and increasing physical frailty, the consequent or threatened loss of independence as a result of these, as well as the social isolation potentially accompanying loss of independence, compounded by bereavements and movement to institutional or other supported accommodation.

While the traditional definition of 'older age' for mental health care has been 65 years or over ('post-retirement'), this has always been problematic because the cut-off point falls in the middle of the first transition and, for most people, some way short of the second. It also fails to reflect an increasingly flexible retirement age. However, 'older age' still needs to be defined. Increased flexibility may offer advantages; however, there is a very real danger that services designed to focus on the needs of older people may come under threat as a consequence.

The following features particularly distinguish 'older age' from 'working age' mental health:

# ■ Different mental disorders:

Dementia is predominantly seen in older age and therefore inevitably shapes service needs. Although this chapter focuses specifically on other mental disorders, dementia remains relevant because:

- it is frequently co-occurring (and sometimes causal)
- it frequently requires consideration as an alternative diagnosis in clinical care
- it affects treatment decisions.

### Different presentations:

Depressive and psychotic disorders arising in older people have differences in symptom profiles and manifestations from those seen in earlier adult life.

### Different contexts:

Physical disorders and social isolation are risk factors for depression at any age; however, because they are particularly common in older populations, they are much more frequently co-occurring, particularly in settings such as medical wards and care homes.

This chapter summarises key features of mental disorders, their impact and their management in older people. The focus, as mentioned, is on disorders other than dementia. Although it is a common disorder with a substantial individual and societal impact, recent interest in dementia – such as the three-pronged advance of the National Dementia Strategy, the Prime Minister's challenge on dementia and the G8 Dementia Summit – has placed it centre stage. Other important dimensions of mental health in later life consequently risk eclipse.

# Mental disorders and their epidemiology and impact in older age

Some people achieve old age without ever experiencing mental illness. Others may have lived through periods of mental disorder or carry an 'enduring illness'. Many people will live through their later years without mental health problems, but 15% will experience short or longer-term difficulties.<sup>26</sup>

# **Depression**

Around 10-20% of people aged 65 and over have depression 'of clinical significance' i.e. at a level where a clinician would expect to intervene.<sup>10</sup> In care homes and general hospital wards, 20–30% will be affected;<sup>11,12</sup> the total is higher still, at 30–50% in people with age-related conditions such as stroke and Parkinson's disease.<sup>27,28</sup>

Across the adult age range, the prevalence of depressive disorders increases from young to mid-adult age groups, followed by a noticeable fall in prevalence for older people within a decade of retirement age.<sup>29</sup> The immediate post-retirement period is therefore one where the mental health of the population as a whole is relatively good, although people who have taken early retirement have worse mental health than those who are still working.<sup>30,31</sup>

National mental health surveys have tended to have insufficient numbers in the oldest age groups to investigate depression trends across post-retirement age groups, for example, the 1993 National Psychiatric Morbidity Survey only covered the 16–64 age range; the 2000 survey covered the 16–74 range; and only the 2007 survey removed the upper age restriction (as will be the case in the forthcoming 2014 survey). Studies of depression in post-retirement age groups show an increase with age.<sup>32</sup> Depression is more common in women than men, although this gender difference is substantially less than that seen in younger age groups; the association with marital status differs by gender, with marriage being protective for men but associated with higher risk among women.<sup>33</sup>

Social isolation and worse physical health are risk factors for depression in any age group, but are particularly important in older age because they are more common and therefore account for a higher proportion of cases. For example, around 10% of people aged 65 years and over in England reported that they were lonely often or all the time, 34,35 and 5 million reported that television provided their main company. As well as having a higher risk of depression and suicide, 99 lonely people visit their GP more and have higher use of medication, higher incidence of falls and increased risk of entering long-term care. The higher risk of depression in people with physical disorders is particularly related to a health condition's impact on daily activities, 42 although depression is more common following stroke than

would be expected from the level of disability.<sup>43</sup> Worse physical health is a stronger risk factor for older people who are already socially isolated<sup>44</sup> and affects the risk of developing depression, whereas social support has more of an influence on someone's likelihood of recovery from depression.<sup>44,45</sup>

There is no evidence that older and younger people with depression differ in their response to antidepressants<sup>13,46</sup> or psychological treatments.<sup>14</sup> Therefore, the key issue remains one of access to treatment.<sup>15</sup> As well as its co-occurrence with physical disorders, depression beginning after age 65 more often features hypochondriasis, bodily pains and gastrointestinal symptoms.<sup>47</sup> Furthermore, depression also predicts adverse outcomes in other health conditions such as myocardial infarction,<sup>5</sup> stroke<sup>6</sup> and hip fracture.<sup>7</sup> These associations are not age-specific, but naturally have higher salience in older people in whom physical disorders have a more immediate potential impact on survival and independent living.

People with depression have higher mortality in post-retirement as well as in younger age groups.<sup>48</sup> This is primarily accounted for by natural causes<sup>49</sup> and may reflect not only adverse health behaviours and conditions such as cardiovascular disease, but also delayed diagnosis of life-threatening conditions and reduced treatment access. Suicide is relatively rare compared with other causes of death in later life,<sup>50</sup> although it is strongly associated with depression.<sup>51</sup> It is potentially amenable to preventive and treatment strategies by providing support after adverse life events, including bereavement and physical illness, and the identification and treatment of depression.<sup>52</sup> Encouragingly, suicide rates among older people in the UK are falling.<sup>53</sup>

# **Psychosis**

Psychotic symptoms, such as delusions and hallucinations, are seen in a number of conditions, including severe depression, dementia and delirium.<sup>54</sup> Psychotic symptoms that occur in dementia cause distress to caregivers<sup>55</sup> and are commonly associated with institutionalisation.<sup>56</sup> Psychotic symptoms are seen in around 10% of nursing home residents.<sup>19</sup>

Severe mental disorders such as schizophrenia and bipolar disorder follow a chronic or relapsing course in many people and thus often endure into late life. The loss of life expectancy faced by people with severe mental disorders is increasingly recognised,<sup>57</sup> and health disadvantages persisting into older age complicate the management of the mental disorder as physical frailty increases. Many are well-recognised risk factors for dementia.<sup>58–60</sup> The mortality gap between people with severe mental disorders and the general population has widened considerably in England and Wales, and this divergence was strongest in the 65 and over age group.<sup>21</sup> Suicide risk is also raised into mid-life at least.<sup>61</sup>

As well as pre-existing problems persisting into late life, a considerable number of schizophrenia-like disorders arise for the first time in older age, with annual first contact rates of around 20 per 100,000;20 this proportion increases 10-fold

in some minority ethnic groups.<sup>62</sup> These disorders remain relatively poorly understood and under-researched, with some distinct symptom profiles and risk factors, including an association with deafness and other sensory deficits.<sup>63</sup> A Cochrane review cited an inadequate evidence base around antipsychotic treatments,<sup>64</sup> and non-pharmacological approaches in older age have focused on pre-existing schizophrenia<sup>65,66</sup> rather than late-onset disorders. The National Institute for Health Research antipsychotic treatment for very late-onset schizophrenia-like psychosis (ATLAS) trial is under way and will report in 1–2 years.<sup>67</sup>

The distinction between schizophrenia and dementia is important in older adults because of the risks associated with antipsychotic medication in Alzheimer's disease<sup>68</sup> and the potentially catastrophic consequence of irreversible Parkinson's disease in Lewy body dementia. The differentiation between late-onset psychosis and delirium may also be complex.

People with late-onset schizophrenia often have significant paranoid symptoms and are difficult to engage in treatment, although the symptoms themselves are frequently distressing. There is little or no evidence available on the condition's impact or the most appropriate treatment approaches.

# Alcohol and substance misuse

Alcohol abuse or dependence is present in 2–4% of people aged 65 and over and hazardous drinking in 10%.<sup>18</sup> Illicit substance use is still uncommon, although it is increasing in pre-retirement age groups and may in time become a more prominent context for older people's mental health care.<sup>69</sup>

Alcohol misuse is important in older people not only because of its direct effects on physical and mental health, but also because of the ways in which it complicates the management of other co-occurring conditions, for example, increasing medication side effects, risk of falls, cognitive impairment and cardiovascular disease.

Excessive use of alcohol and other substances by older people has been overlooked.<sup>18,70</sup> It requires a more enlightened service response, and focusing on groups at particular risk may reduce morbidity and mortality.<sup>71</sup> The USA has a treatment intervention protocol guide for substance misuse services for older people,<sup>72</sup> but comparable strategies have yet to be developed in the UK.

# Service contexts

As well as primary care and secondary mental health services, general hospital wards are an important environment in which mental disorders manifest in older people, as are care homes. Many people with mental disorders in the community may have more contact with social services than health services because of co-occurring dementia and/or physical frailty. (For online resources related to service contexts, please see Box 8.1.)

# **Primary care**

Recent Department of Health policy on improving mental health service accessibility highlights the fact that fewer than one in six older people with depression ever discuss this with their GP.<sup>15</sup> Indeed, primary care identification and treatment of mental disorders in older people has been a concern over many years. 16,17 The Royal College of General Practitioners has issued guidelines on the management of depression in older people,<sup>73</sup> but their impact on practice has not been evaluated. There are several examples of successful collaborative care interventions for late-life depression both internationally<sup>74,75</sup> and in the UK,76 as well as in contexts relevant to older people such as chronic illness and diabetes<sup>77,78</sup> and in posttraumatic stress disorder.74 However, these focus on people who are recognised to have mental disorders and do not address the issue of under-recognition. While primary care screening for depression has been claimed to have limited benefit in general because of the small numbers of people identified,<sup>79</sup> even in high-risk samples,<sup>80</sup> there is a clearer rationale in older people because of low identification rates. and a trial is under way to evaluate the potential utility of managing mild depression.81 There may be opportunities for promoting recognition of depression in older age groups specifically focusing on the most salient risk factors – social isolation and physical ill health - which are often known to the GP, and would thus be an obvious target for raising awareness of risk.

The World Health Organization provides a case study of integrated mental health care for older people in Sydney, Australia (see www.who.int/mental\_health/policy/services/ Australia.pdf).

# **Community mental health teams**

Mental health of older adults (MHOA) community mental health teams (CMHTs) are regarded as pivotal to the delivery of an integrated service, 82 offering specialist assessment and treatment to older people and their carers in their own homes and other community settings.83 CMHTs provide continuity of care and co-ordination within mental health.84 A 2010 survey observed improved MHOA CMHT access since 2004, but wide variation in staffing, and continuing low access to psychology services.85

Good practice guidelines commonly advise that secondary mental health services provide support for staff working in mainstream settings.<sup>12,83</sup> In the past, this role has typically fallen to CMHTs for older people, a role which has grown over the past 15 years.<sup>86,87</sup> The extent to which CMHTs can continue to support such a wide range of services is questionable within an ever-increasing remit and limited budget.<sup>88</sup> This has led to increasing interest in specialist services for some of these settings, notably general hospital wards and care homes.

# **General hospital care**

As described above, mental disorders such as depression may be both causes and consequences of physical health conditions, as well as potential complicating factors in their care and predictors of worse outcome. Depression is unsurprisingly common in older people on general medical wards. Delirium and dementia are also common Both may present with depressive or psychotic symptoms, as may hazardous alcohol use. Because of the profound impact delirium has on outcome, interventions to prevent or minimise it need urgent development and evaluation. In addition, cost-effectiveness of depression interventions has been demonstrated after hip surgery and in older people with diabetes.

The three common presentations of depression, delirium and dementia map much more closely to the skill sets of MHOA services than general liaison psychiatry, and many older general hospital inpatients are already known to MHOA CMHTs. Following a 2002 survey indicating a widespread dissatisfaction with MHOA CMHT input to general hospitals,96 the influential 2005 Who Cares Wins report<sup>12</sup> highlighted the need for dedicated MHOA liaison services and led to a substantial national growth in provision, albeit with widely varying staffing.97 Economic benefits associated with the introduction of the Birmingham rapid assessment, interface and discharge (RAID) service for all adults<sup>24</sup> predominantly lay in reduced length of hospitalisation of older people. 98,99 However, recent Joint Commissioning Panel for Mental Health commissioning advice on liaison service provision made little mention of the needs of older inpatients, 100 suggesting continued marginalisation.

# **Care homes**

Care home residents also have high levels of frailty and physical health problems, as well as the additional stressors of loss of independence and institutional care. Delirium is present in around 15%101 and dementia in over 70%.102 Depression and psychotic symptoms are common and often secondary to dementia. As well as directly impacting on the quality of life of the person affected, depression and psychosis may impact on the staff required to provide care, although the determinants of care home staff satisfaction appear to relate more to the home environment than residents' behaviour. 103 Currently mental health care in care home residents is predominantly reliant on primary care input with CMHT support. Dedicated mental health care home support teams have the potential for providing longerterm engagement of care home staff with the possibility of education and skills development. However, provision remains patchy and relatively unevaluated.104

# Policy context and the voluntary sector

MHOA has frequently fallen between health policy initiatives which have focused either generically on mental health across all age groups or, in older adults, on dementia. For example, *Closing the Gap* only mentions improved access to psychological therapies as a target for older people, and the statements around better integration of physical and mental health care make no mention of older adults – also the case for physical health objectives in *No Health Without Mental Health*. Reducing isolation in older people is recommended in the latter, but no solution is proposed. The most comprehensive consideration to date remains the 2001 National Service Framework for Older People (Standard 7), which covered specified mental health service needs, integrated care and standardisation of assessments – but which will soon be 15 years old.

Mental disorders in older people also do not match well with the pattern of voluntary sector provision, and lack of focused advocacy may partly underlie the poverty of policy coverage. Mental health charities have to serve all age groups and understandably tend to focus their attention on younger adults, while dementia charities naturally focus on these disorders. Age UK remains the most relevant voluntary sector organisation for other mental disorders in older age, but its remit is necessarily broad. (For online resources related to policy context, please see Box 8.1.)

# Box 8.1 Service contexts, policy and professional context: resources

### **Primary care**

Case study: integrated mental healthcare for older people in Sydney <a href="http://www.who.int/mental\_health/policy/services/">http://www.who.int/mental\_health/policy/services/</a> Australia.pdf

# **General hospital care**

Quality standards for liaison services (including those for older adults) <a href="http://www.rcpsych.ac.uk/pdf/Standards%204th%20">http://www.rcpsych.ac.uk/pdf/Standards%204th%20</a> edition%202014.pdf

# **Care homes**

- BGS Quest for Quality report on the need for better care home input, 2011 <a href="http://www.bgs.org.uk/campaigns/carehomes/guest\_quality\_care\_homes.pdf">http://www.bgs.org.uk/campaigns/carehomes/guest\_quality\_care\_homes.pdf</a>
- SCIE guide, 2006 assessing the mental health needs of older people <a href="http://www.scie.org.uk/publications/guides/guide03/law/standards.asp">http://www.scie.org.uk/publications/guides/guide03/law/standards.asp</a>
- CPA 2009 report on ageism, highlighting lack of mental health training in care homes http://www.cpa.org.uk/information/reviews/CPAageism and age discrimination in mental health care-report.pdf

# Policy context and the voluntary sector

- NSF for Older People <u>https://www.gov.uk/government/publications/</u> <u>quality-standards-for-care-services-for-older-people</u>
- Age UK befriending service http://www.ageuk.org.uk/health-wellbeing/ relationships-and-family/befriending-servicescombating-loneliness/

# Professional context and a redefinition of 'older age'

- RCPsych guide for commissioners of older people's mental health services <a href="http://www.jcpmh.info/wp-content/uploads/jcpmh-olderpeople-guide.pdf">http://www.jcpmh.info/wp-content/uploads/jcpmh-olderpeople-guide.pdf</a>
- PSSRU 2008 report on age discrimination in mental health services http://www.pssru.ac.uk/pdf/dp2536.pdf

# Professional context and a redefinition of 'older age'

Specialist mental health services for older people began to develop in the UK from the late 1960s in response to an ageing population, recognition of the particular needs of older adults and the failure of existing services to provide adequately or appropriately for them. In 1989, the Department of Health recognised 'old age psychiatry' as a specialty. By then much had already been achieved to create better services.<sup>105</sup> At the millennium, the UK was one of only three nations with a wide range of mental health services for older people,106 with well-established outreach and linkage functions, providing more integrated care. MHOA service provision traditionally defined itself by the 65 and over age cut-off; however, the introduction of the Equality Act 2010 in the UK<sup>107</sup> has rendered this problematic. The absence of a robust definition suited to the new era risks erosion and fragmentation of current services, with some health providers reverting to generic all-age (so-called 'ageless') services. 108 (For online resources related to policy context, please see Box 8.1.)

A broad range of stakeholders and service users in Central and North West London NHS Foundation Trust were convened to discuss redefining criteria for access to old age psychiatry services. They devised needs-based criteria, characterising people most likely to benefit from a specialist service. These criteria have been adopted by the Old Age faculty of the Royal College of Psychiatrists, have been approved by the College Council and have the support of a broad range of national stakeholders:<sup>109</sup>

- People of any age with a primary dementia.
- People with mental disorder and physical illness or frailty that contributes to, or complicates the management of, their mental disorder. This may include people under 65 years old.
- People with psychological or social difficulties related to the ageing process, or end-of-life issues, or who feel their needs may be best met by an older adult service. This would normally include most people over the age of 70.

# Conclusion

Mental health problems in older people are common and often undiagnosed, but very often they are as amenable to established treatments as mental health problems in other age groups. Helping people with combined physical, psychological and social difficulties in the context of ageing and end of life demands specialism. 109,110 This is likely to be substantially compromised by any move to generic 'ageless' services – both in terms of the immediate loss of specialist provision and in the longer-term loss of specialist training. No Health Without Mental Health expects services to be age-appropriate and non-discriminatory.<sup>111</sup> The challenge is to create and sustain services, across health and social care, which are responsive to the particular needs of older people, do not disadvantage them and do not contravene the law, and which maximise patient choice within available resources.84

# What do we need to know?

- Have successive policy statements and initiatives achieved any improvement in primary care identification of depression in older adults? If not, are there alternative means of achieving this?
- What would be the effectiveness of targeting heightened depression awareness (with or without screening) by primary care services for older people with frailty or social isolation?
- Can loneliness be improved in older people? If so, does this reduce the risk of developing depression?
- The management of late-onset psychosis is currently an evidence-free zone. There is inadequate information on the personal, social and healthcare impact of late-onset psychosis, and no evidence to guide service delivery and engagement strategy. This needs to be corrected.
- Further evidence is needed on the best ways to promote mental health in care homes, the majority of whose residents have mental health difficulties, particularly dementia. Are there policies (e.g. around commissioning) which might promote a more collaborative approach between mental and physical health services?
- The focus for MHOA services is increasingly moving towards the second 'ageing' transition mentioned in the introduction. There is currently little provision for people at or around retirement age, whose needs fall between MHOA and working-age adult services. Although community mental disorder prevalence is relatively low for the post-retirement decade, mental health issues around this time may have an enduring impact on later old age. Therefore at least some evaluation of optimal service models needs to be considered.

# Authors' suggestions for policy

- It is self-evident that 'older age' is characterised by health conditions that are multiple, overlapping and interacting. Any attempt to sub-divide services for older people by diagnosis poorly reflects patients' experiences and should be viewed with caution. This includes the separation of dementia services from those for other late-life mental disorders, resting as it does on the false assumption that these can be routinely distinguished.
- On the other hand, specialisation by context may be fruitful, particularly when directed to settings poorly served by existing services. This has been demonstrated in general hospital settings through MHOA liaison service development, and would be worth considering further for the under-served care home sector. It also applies to specialist dementia diagnostic services, although longerterm care for dementia needs to be holistic because of co-morbidity and changing needs.
- Initiatives promoting closer working between MHOA and elderly care services should be considered as a priority. Close and productive relationships developed through co-working in general hospitals might be usefully extended to collaborations on enhanced care home support. Unfortunately, competition between mental health and acute care trusts for limited resources will not promote collaboration in service design unless specifically encouraged as part of the commissioning process. Linking health and social care should be a priority, perhaps also enshrined in joint commissioning.
- Mental health care for older adults emerged as a specialty because people in post-retirement age groups were poorly served by generic mental health services. Any return to 'all-age' mental health service provision is retrogressive and potentially discriminatory. It has substantial long-term implications, and should not proceed unless there is clear evidence of benefit.

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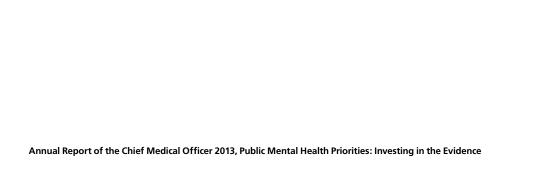
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Section 4

# The economic case for better mental health



## Chapter 9

# The economic case for better mental health

#### **Chapter authors**

Martin Knapp<sup>1</sup>, Valentina lemmi<sup>2</sup>

- 1 Professor of Social Policy and Director, Personal Social Services Research Unit, London School of Economics and Political Science
- 2 Research Officer, Personal Social Services Research Unit, London School of Economics and Political Science

#### Key statistics

- In 2000, 90% of the societal cost of depression was due to unemployment and absenteeism.¹
- In 2000, the service costs associated with childhood psychiatric disorders were 12 times greater for frontline education services than for specialist mental health services.<sup>2</sup>
- Over 25 years, the total return from parenting programmes for children with conduct disorder is between 2.8 and 6.1 times the intervention cost, much of this through reduced crime.<sup>3</sup>
- Early intervention services that provide intensive support for young people experiencing a first psychotic episode can help avoid substantial health and social care costs: over 10 years perhaps £15 in costs can be avoided for every £1 invested.<sup>4</sup>
- £1 in every £8 spent in England on long-term conditions is linked to poor mental health.<sup>5</sup>
- More than 11% of the NHS budget is spent on treating mental illness<sup>6</sup> but the indirect costs from unemployment, absenteeism and presenteeism can be higher. These indirect costs totalled £30.3 billion in England in 2009/10 across all mental illnesses, compared with direct health and social care costs of £21.3 billion.<sup>7</sup>
- The economic cost of a completed suicide for someone of working age in the UK exceeds £1.6 million.8

#### Overview

Mental illness can emerge at any age, and can have highly significant impacts across much of the life course for the individual, their family and community. Those impacts may start early in life – maternal mental illness can negatively affect a child's later emotional, behavioural and intellectual development – or may strike late; for example, the consequences of bereavement can last many years.

Emotional and behavioural problems that develop in childhood can leave a legacy of difficulties that stretches long into adulthood. The typical age of onset of serious psychoses such as schizophrenia and bipolar disorder – in late adolescence and early adulthood – is also the time when many key investments and decisions are made that shape future careers, personal and social roles.

People with mental health problems are more likely to smoke, be overweight, have disrupted education, be unemployed, take time off work, fall into poverty, and find themselves in the criminal justice system. Major mental disorders shorten the life span. As other chapters in this report make clear, and as we describe below, no field of social policy is untouched by mental illness.

While it is the health and quality of life consequences of mental illness that rightly dominate public concerns,<sup>9</sup> it is the economic consequences that most heavily influence policy

responses. This is not because the dominant policy aim for public mental health is to save resources, but because those people who make, shape and implement policies recognise that those resources are always scarce relative to the demands made upon them – especially so when there are broader economic pressures. <sup>10</sup> Decision makers want preventive strategies and treatment approaches to be effective in improving health and quality of life, but they also want to get good value for money.

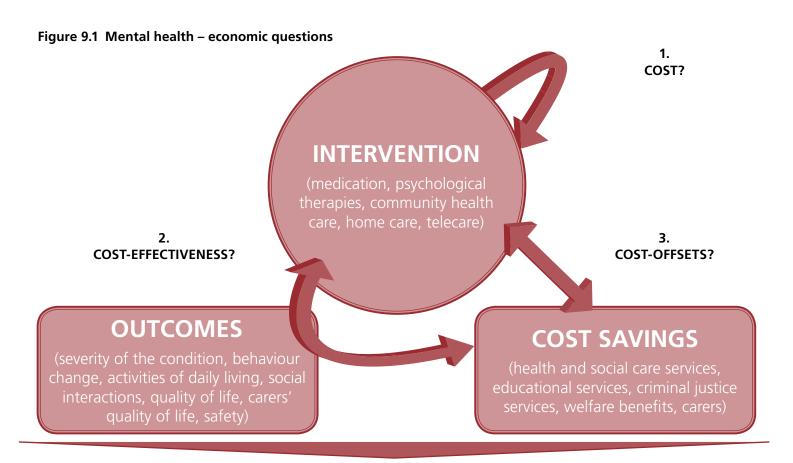
We address this value for money question by examining the economic case for better public mental health. Making the economic case does not mean cutting costs but rather using resources (not just in the NHS, but across the whole economy) to their best effect – making sure they are used to get the best achievable health and quality of life outcomes. We discuss a series of economic opportunities and challenges. Between them, they reflect the key characteristics of mental health problems: distressing and disabling symptoms; chronicity if untreated; high rates of co-morbidity; effects on many aspects of individuals' lives; spillover effects on families and communities; disrupted employment; associations with anti social behaviour and crime; links to self-harm and suicide; widespread stigma, discrimination and victimisation; and interconnections with socio-economic disadvantage and inequalities. We shall demonstrate how economic arguments can support the case for prevention and treatment.

#### Making an economic case

#### Scarcity and choice

Healthcare and other responses to the needs of people with mental health problems that are well designed, well coordinated and well targeted will have significant impacts on their symptoms, functioning and quality of life, and may also improve the quality of life of family members and others. The problem is that there are never enough health or other services to meet all needs or satisfy all preferences. This endemic scarcity leads to difficult decisions about how best to achieve good clinical and quality of life outcomes, in turn raising questions about how to use resources efficiently and equitably – criteria that we define below. These are moral, political and perhaps even ethical questions; but they are also economic questions.

A simple framework (Figure 9.1) shows common interventions (shorthand for treatments, support arrangements, preventive strategies or wider policy frameworks), their potential health and other outcomes, and the consequences of those outcomes for resource use patterns and costs. Interventions that improve outcomes may reduce longer-term costs: for example, treating the early signs of psychosis could reduce positive symptoms and keep patients engaged in education or employment, thereby avoiding the need for inpatient admissions (or shortening their duration) and reducing productivity losses from absenteeism or long-term unemployment.<sup>4</sup>



4. INCENTIVES?

Source Martin Knapp, London School of Economics and Political Science

Figure 9.1 also shows how economic analysis helps us understand and improve mental health systems (see also World Health Organization, 2006). There are four questions that economists often address. **Cost** questions focus on the resources used to provide treatment, care and support. **Cost-offset** questions ask how those costs compare with the savings resulting from successful treatment or prevention. **Cost-effectiveness** questions ask about links between the resources expended and the outcomes achieved. **Incentives** questions address ways to encourage decision makers to pursue policies or practices that are effective, efficient and fair.

#### **Cost-effectiveness**

The cost-effectiveness question is the most relevant, and embodies the cost and cost-offset questions. For two or more interventions or strategies (one of which could be doing nothing), a cost-effectiveness analysis compares the resources used by each (the costs) with the health, quality of life or other outcomes achieved (the effectiveness). If one intervention has both lower costs and greater effectiveness than the other, it will look attractive to hard-pressed budgetholders, although their ultimate decisions will also factor in fairness and other wider strategic considerations. However, if one intervention is more effective than the other but only at a higher cost, then someone must decide whether those better outcomes are worth the additional expenditure.<sup>12,13</sup> There

is no simple way to judge such 'worth': it is in the eye of the beholder, and different beholders might reach different judgements.

An intervention does not need to save money to be costeffective. However, it does need to generate outcomes that are 'worth' paying for, which means that the outcome gains are greater than would be achieved by using the resources in any other way. Someone must weigh up the relative outcomes and costs, and make the trade-off. Politicians are elected to make these decisions strategically, and commissioners and providers are entrusted with responsibility locally. Each can be guided by evidence from well-conducted research and also (in England and Wales) by the National Institute for Health and Care Excellence (NICE), which synthesises evidence and combines it with expert advice to produce clinical guidelines. These guidelines (for example, on depression, psychosis and schizophrenia)<sup>14,15</sup> are increasingly the mainstay of commissioning and provision across many clinical areas, and build explicitly on economic evidence.

Where possible, NICE uses a generic health outcome measure – the quality-adjusted life year (QALY) – alongside disease-specific measures. The QALY is intended for use across all clinical areas, allowing broad resource allocation decisions to be made. NICE also recommends a threshold value: an intervention that costs more than £30,000 per QALY is unlikely to be considered 'worth it' because it is believed

that the money could be better spent elsewhere in the NHS (NICE, 2008). This approach works less well in areas such as schizophrenia, where QALYs are hard to measure reliably, <sup>16</sup> and often needs adaptation in public health and social care contexts where health improvement is not the only or even the most important objective.

Evidence on cost-effectiveness can be generated from various study designs. The randomised controlled trial (RCT) is usually best, but observational designs have also been used<sup>17</sup> and mathematical or statistical modelling is now widely employed to supplement and extend RCT findings.<sup>18</sup> Modelling also offers a short-term substitute for an RCT when decision makers need evidence sooner than a trial can deliver – such as when projecting the economic impact of closing a hospital from data on early discharges into the community<sup>19</sup> – and also an alternative when a trial is infeasible, such as when evaluating a nation-wide policy.<sup>20</sup>

Cost-effectiveness analyses helpfully remind everyone – health professionals, patients, carers, taxpayers and voters – that resources are finite and so commissioners and other key decision makers face difficult choices in deploying them. Those analyses also tell us that it is sometimes worthwhile to choose an option even when it does not save money.

#### **Efficiency and equity**

Cost-effectiveness and related analyses address questions of efficiency: how to get the maximum effect in terms of outcomes achieved from a specified volume of resources (such as the available budget). Efficiency is not the only objective of a healthcare system or nation, of course. Another important objective is equity, which relates to the extent to which outcomes, access to services and payments for them are distributed fairly across individuals, regions or socioeconomic strata. Different people will have different views on what is fair, but most would agree that equity should not mean exact equality: people have different needs and an equitable allocation of resources should result in giving more treatment and support to those with greater needs. Similarly, individuals have different income and wealth levels, and most countries expect those who are better off to contribute greater amounts (for example, through taxes for the UK's centrally funded NHS).

Most mental health systems are neither efficient nor equitable: they do not get the most out of available resources, and they would not be considered by most citizens to be distributing their benefits or burdens in ways that are fair.<sup>21–23</sup>

## Economic opportunities and challenges

#### **Distress and disability**

The Global Burden of Disease Study 2010 reports 'the striking and growing challenge that [mental] disorders pose for health systems in developed and developing regions'.<sup>24</sup> Specifically for the UK, figures for 2010 show 'the growing burden of disability, particularly from mental disorders, substance use, musculoskeletal disorders, and falls [which] deserve an integrated and strategic response'.<sup>25</sup>

Economists also measure the consequences of mental health problems using cost rather than disability weights, summing the costs of services and treatments, reductions in productivity from disrupted employment, the imputed values of unpaid care, and lost economic value from premature mortality. The resultant figures do not provide guidance on how to prevent or treat illness, but help by emphasising to decision makers the scale of the challenge and its distribution across the economy. <sup>26</sup> For example, Thomas and Morris¹ calculated that 90% of the societal cost of depression was due to unemployment and absenteeism, and Snell et al. <sup>2</sup> showed how the service costs associated with childhood psychiatric disorders were 12 times greater for frontline education services than for specialist mental health services.

#### **Enduring impacts**

Mental health problems in childhood or adolescence can have later-life consequences: antisocial and criminal behaviour, substance misuse, unemployment, social exclusion, emotional disorder and poor quality of life (see Chapter 6 of this report, 'Life course: children and young people's mental health'). Each of these has attendant costs. <sup>27–29</sup> Evidence suggests that NHS-delivered interventions in childhood could have substantial longer-term impacts, although their biggest economic pay-offs may be outside the NHS. Bonin et al.<sup>3</sup> calculated that, over 25 years, the total return from parenting programmes for children with conduct disorder is between 2.8 and 6.1 times the intervention cost, much of this through reduced crime. Beecham<sup>30</sup> reviews related economic evidence.

The onset of psychosis in adolescence or early adulthood can seriously disrupt education and post-school training, causing poor educational outcomes and poor employment prospects. Leaving the psychosis untreated exacerbates the situation and raises the risk of suicide (see Chapter 15 of this report, 'Suicide and self-harm'). Early intervention services that provide intensive support for young people experiencing a first psychotic episode can reduce relapse rates and improve both vocational recovery and quality of life. They help avoid substantial health and social care costs: over 10 years perhaps £15 in costs can be avoided for every £1 invested.

The chronicity of most mental health problems and the potential for long-term deleterious impacts across many life domains should be enough to energise searches by all

interested parties for early effective action – but, as we have illustrated, there is also often a supportive economic case. A major challenge that we would identify is how to get decision makers to think long term, even with short-term resource pressures arising from the need to keep within tight expenditure constraints.

#### **Co-morbidities**

People with schizophrenia and psychosis have higher risks of physical morbidity and premature mortality, linked particularly to poor health behaviours. Yet they also have poorer access to routine health checks (see Chapter 13 of this report, 'Physical health and mental disorder'). There are economic as well as clinical and ethical reasons for recognising and responding to these links, since poor physical health translates into increased and enduring NHS costs.

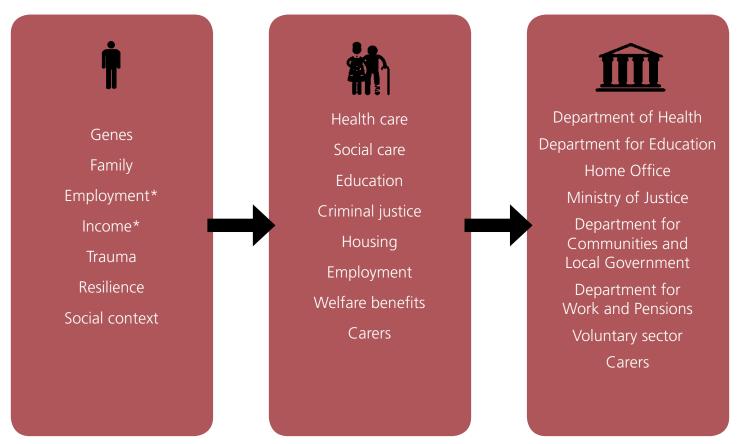
Evidence on the economic case for action is modest but accumulating, as we now illustrate. Adding bupropion to cognitive behavioural therapy (CBT) and nicotine replacement therapy can help people with first-episode psychosis to quit smoking and appears to be cost-effective.<sup>33</sup> A combination of psycho-education and nutritional and/or exercise counselling appears to be a cost-effective way to help people with first-episode psychosis to manage their weight,<sup>34</sup> while a sixmonth manualised healthy lifestyle programme appears cost-effective as a means of managing body mass index for people who have been living with schizophrenia for longer.<sup>35</sup>

Depression is also commonly associated with poor physical health (see Chapter 13 of this report, 'Physical health and mental disorder'). Compared with people with diabetes alone, those with co-morbid depression and diabetes are four times more likely to have difficulties managing their health, and seven times more likely to miss work frequently.<sup>36</sup> The economic consequences for health and other sectors can be considerable,<sup>37</sup> although 'collaborative care' delivered in primary care settings to individuals with this co-morbidity (involving GP advice and care, antidepressants and sometimes CBT, with a practice nurse as case manager) appears to be cost-effective.<sup>38</sup>

More broadly, given that many people with poor longterm physical health also have mental health problems, the resultant NHS costs can be substantial. Naylor et al. (2012) conservatively estimated that £1 in every £8 spent in England on long-term conditions is linked to poor mental health.<sup>5</sup>

There are also close links between such co-morbidities and deprivation, thereby exacerbating the inequalities between socio-economic groups if treatment is not offered. As well as collaborative care arrangements, innovative forms of liaison psychiatry in acute hospitals can be cost-effective.<sup>39</sup> Better integration of physical and mental health care, encouraged by redesigned payment mechanisms, would further improve healthcare quality and productivity.

Figure 9.2 Mental health – multiple needs and impacts



Notes \* Economic factors

Source Martin Knapp, London School of Economics and Political Science

#### Multiple needs and impacts

Mental health problems can generate major and enduring impacts, and these can be experienced across many aspects of an individual's life, generating needs for support from (potentially) the social care, housing, employment, criminal justice, income support and other systems (Figure 9.2).<sup>7,40–42</sup> The direct treatment costs to the NHS are certainly substantial – more than 11% of the NHS budget is spent on treating mental illness<sup>6</sup> – but the indirect costs can be even higher. Indirect costs – mainly from unemployment, absenteeism and presenteeism – amounted to £30.3 billion in England in 2009/10, compared with direct health and social care costs of £21.3 billion.<sup>7</sup>

One obvious corollary is the need for co-ordinated action across budgets and systems to avoid gaps and wasteful overlaps, combining resources effectively and efficiently.<sup>43</sup> Silo budgeting – where budget-holders are so determined to keep their own spending in check that they engage in cost-shifting and problem-dumping onto other budgets – is a substantial barrier to better overall efficiency. Silo budgeting is likely to be more common when resources are under considerable pressure, and yet the greater those pressures, the stronger the need for co-ordinated action across different areas. A recent, far-sighted example is the decision by a police commissioner in England to invest in psychologist-delivered parent training programmes to tackle conduct disorder because of the potential to cut antisocial behaviour and crime-related costs over future decades, as demonstrated by Bonin et al.<sup>3</sup> Another example is investment in workplacebased mental illness prevention and treatment programmes by some larger companies (and some public sector employers), with the potential to reduce both absenteeism (thereby improving productivity) and NHS costs.<sup>44</sup> Great strides have also been made in supporting people with a history of severe mental health problems to achieve open employment, with cost-effectiveness gains.38

#### Impacts on others

Mental health problems experienced by expectant and new mothers can have deleterious consequences for their partners and children, some with measurable associated costs. 45,46 Behavioural problems in schools can damage the education experience for other pupils. The relatives of people with schizophrenia may give up employment, take time off work to provide support (thereby losing earnings) or give up leisure time or incur out-of-pocket costs to subsidise treatment expenses or provide transport to appointments. These are largely hidden costs, but to overlook them in policy discussions would be dangerous given that many people with mental health problems rely on their family members and communities for support.

Population ageing makes this an especially important issue, since models of treatment and care that are reliant primarily on paid professionals may not be affordable in future decades.

Interventions can be targeted on family members or intrafamily relations, as with family therapy for schizophrenia, for which there is both a clinical and an economic case.<sup>35,47</sup> Some interventions can be justified not only by their effects on those individuals who are ill, but also because they recognise and address the spillover effects of mental illness on other people: for example, CBT and person-centred treatment for postnatal depression can have benefits that go beyond symptom relief for mothers so as also to improve the lives of their children, and in a cost-effective way.<sup>48</sup> There are also interventions that build explicitly on community assets, as with befriending programmes,<sup>49,50</sup> and interventions that can employ people with lived experience of mental illness to deliver support, as with peer workers.<sup>51,52</sup>

#### **Employment**

There are multiple and two-way links between mental health problems and employment difficulties. People with a history of mental illness are at greater risk of unemployment, job insecurity, early retirement, absenteeism, presenteeism and low salaries, while stress, bullying and other adverse workplace experiences are risk factors for the onset or exacerbation of common mental disorders (see Chapter 10).

Employment generates earnings, brings social status, shapes social roles, fosters social participation and is a major factor in self-image and self-esteem. Long-term unemployment increases the risk of unmanageable personal debt and poverty, in turn further worsening mental health.<sup>53</sup> Most people with a history of mental illness want to work, are perfectly capable of working in appropriate settings, and derive therapeutic benefits from working.<sup>44,54</sup> But those people often face barriers: reduced abilities because of their symptoms (even if only temporarily), endemic social stigma and widespread discrimination by employers.

Economic hardship intensifies the difficulties that people with mental health problems encounter in the labour market. A study that looked at experiences across 27 countries of the European Union found that it was harder for people with mental health problems to get employment during the worldwide macroeconomic recession of recent years than people without such morbidity. Moreover, the relative disadvantage was significantly greater in countries with higher levels of stigmatising attitudes towards mental illness.<sup>55</sup>

#### Antisocial behaviour and crime

While, as Howard and Shaw argue in Chapter 14 of this report, 'Violence and mental health', "most people with mental illness are not violent and most people who are violent are not mentally ill", mental health problems may lead to contact with the criminal justice system. As noted earlier, childhood mental health problems can lead to teenage delinquency and adulthood crime. <sup>27,29</sup> Economic impacts include costs associated with the victim, fear of crime, the impacts on the criminal justice system of acquisitive crime by people who misuse substances of and violent crime by people experiencing florid psychotic episodes, <sup>57</sup> and suicide and self-harm by people experiencing severe depression. <sup>58–60</sup>

Economic evidence in this area is limited. Parenting programmes targeted at parents of children with conduct disorder and intervention services for those in the early stages of psychosis look like cost-effective preventive strategies over both the short and long term.<sup>3,4</sup> However, little is known about the economic case for liaison and diversion services or mental health programmes within prisons.<sup>61</sup>

#### Suicide and self-harm

Suicide and self-harm are rare but disturbing consequences of mental illness. Although not uppermost in decision makers' minds when considering how to address these events, there are actually quite high economic consequences too, including intangible costs (the value of lost life; pain and suffering for relatives), as well as the costs of lost productivity (both waged and unwaged), police time and funerals. The cost of a completed suicide for someone of working age in the UK exceeds £1.6 million.8 Self-harm and non-fatal suicide attempts generate costs for Accident & Emergency departments and medical, surgical and psychiatric care.62

Although the economic evidence is sparse, there is some to guide commissioners. Suicide awareness training for GPs and other professionals, followed by CBT for individuals identified as at risk, is highly effective in reducing premature death, self-harm, grief to families and productivity losses. It is also highly cost-effective.<sup>38</sup> Manual-assisted CBT for adults with a history of recurrent deliberate self-harm is also cost-effective,<sup>59</sup> but group therapy for adolescents who repeatedly self-harm is not.<sup>63</sup>

#### Stigma and discrimination

Poor mental health can be exacerbated by social exclusion, discrimination and prejudice.<sup>64</sup> The stigma experienced by many people can affect multiple aspects of their lives, limiting access to employment and housing, harming social relationships, lowering self-esteem and reducing the likelihood that they seek treatment.<sup>65</sup> Initiatives such as England's Time to Change – which included an anti-stigma social marketing campaign – have been launched to try to improve public knowledge, attitudes and behaviour. Time to Change was found to have a modest but statistically significant positive impact, to cost relatively little and to be potentially cost-effective.<sup>66</sup> Earlier modelling obtained similar economic results for the Scottish See Me campaign.<sup>20</sup>

#### **Inequalities**

Unemployment, low income, unmanageable debt, housing problems and social deprivation can lead to or exacerbate mental and physical health problems, suicide rates, alcohol misuse and social isolation, as well as reducing resilience.<sup>67</sup> But there are also causal links in the other direction: people with mental health problems are at elevated risk of unemployment, early retirement, rent arrears and other debt, lower personal and household income and social isolation.<sup>53,68</sup>

One implication of these connections is the need to pay particular attention to mental health needs during periods of macroeconomic downturn.<sup>69</sup> Another implication is that there are wide and deep-rooted inequalities in the incidence and prevalence of mental health needs. Incomerelated inequalities in mental health are much greater than in physical health,<sup>21</sup> and are even greater in some minority ethnic groups.<sup>70</sup>

Decision makers should be alert to the possibility that access to treatments (and hence to their therapeutic benefits) may be inequitably distributed by ethnicity, gender, age, language, religion, income or place of residence.<sup>68</sup> They should also be aware that interventions might be differentially beneficial: Barrett et al.<sup>71</sup> found that adding joint crisis plans to usual treatments was cost-effective in preventing compulsory hospital admissions among black patient groups, but not among white or Asian groups. As we argued earlier, the potential lifelong disadvantages associated with mental health problems require long-term strategic action.

#### Conclusions

Although there is less economic evidence in the mental health field than is needed to support the more efficient and more equitable allocation of available societal resources, the situation is vastly better than even 10 years ago, thanks in large measure to publicly funded research in England. Strategic decision makers and local commissioners now have much more and better evidence to guide their actions. Whether they make best use of that evidence is perhaps another matter. Efforts are needed to improve the translation and implementation of knowledge, to counter some deepseated stigmatising attitudes towards mental illness and the people who experience it, and to address shortages of suitably trained professionals (such as psychologists). Efforts are also needed to engage actors across many sectors – not just health, but social care, housing, education, employment, criminal justice, welfare and so on – given the complex aetiology and wide-ranging impacts of many mental health problems.

Spending on evidence-based mental health services is an investment that will pay quality of life and economic dividends across much of society, over many years.

#### Authors' suggestions for policy

- The potential lifelong disadvantages associated with mental health problems require long-term strategic action.
- Better integration of physical and mental health care, encouraged by redesigned payment mechanisms, would further improve healthcare quality and productivity.
- National and local efforts are needed to address persistent negative attitudes towards mental illness, particularly towards schizophrenia and other psychoses.
- Access to treatments (and hence to their therapeutic benefits) may be inequitably distributed by ethnicity, gender, age, language, religion, income or place of residence.

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## Chapter 10

## Mental health and work

#### **Chapter author**

Max Henderson<sup>1</sup>, Ira Madan<sup>2</sup>

- 1 Senior Lecturer in Epidemiological and Occupational Psychiatry, Institute of Psychiatry, King's College London
- 2 Reader in Occupational Medicine, King's College London

#### Key statistics

- Mental illness costs the UK economy £70–£100 billion per year 4.5% of Gross Domestic Product.<sup>1,2</sup>
- Mental illness is the leading cause of sickness absence in the UK it accounted for 70 million sick days in 2007.²
- Since 2009, the number of working days lost to 'stress, depression and anxiety' has increased by 24%; the number lost to 'serious mental illness' has doubled.<sup>3</sup>
- In 2013, some 40.9% of Employment and Support Allowance recipients had a 'Mental or Behavioural disorder' as their primary condition.¹
- Some 60–70% of people with common mental disorders (such as depression and anxiety) are in work.<sup>4</sup>
- The unemployment rate for people with severe mental illness is four times that of people with no disorder; the rate for more common mental disorders is double.¹
- Only 30% of the UK workforce has access to specialised occupational healthcare.<sup>5</sup>

#### Introduction

Work, its nature, its presence and absence, its quality or lack of it, helps to define individuals to themselves and others. <sup>6,7</sup> Poorly designed work and unemployment are major social determinants of health inequalities and mental illness. <sup>8,9,10</sup> This chapter aims to give an evidence-based, practical, policy-relevant overview of the impact of mental illness on work, and of the impact of work and worklessness on mental illness, and to examine how the workplace may be utilised to improve public mental health.

#### Impact of mental illness on work

#### **Economic impact**

In the United Kingdom (UK), over 130 million working days (113 million in England) are lost to sick leave each year.<sup>3,11</sup> Ill health in the working-age population (aged 16–64 years) costs the economy £13 billion on health-related sickness benefits and £9 billion to employers in terms of sick pay and associated costs.<sup>12,13</sup> Between 2010 and 2013 there were, on average, almost 1 million people each year who took sick leave of longer than 4 weeks. 11 Those off work for more than 6 months have only a 20% chance of returning to work in the next 5 years.14 Mental illness costs the UK economy between £70 billion<sup>1</sup> and £100 billion<sup>2</sup> each year, equivalent to 4.5% of Gross Domestic Product.1 The economic impact of mental illness arises from sickness absence, benefit provision and loss of productivity. The costs generated by caring by partners, children and other family members are more difficult to quantify.

#### Sickness absence

Mental illness results in 70 million sick days per year, making it the leading cause of sickness absence in the UK. 15,16 Since 2009, the number of sick days lost to 'stress, depression and anxiety' has increased by 24%; the number lost to 'serious mental illness' has doubled.3 Although the prevalence of mental illness in the UK in the last 20 years has barely changed,17 mental illness now accounts for more than double the Employment and Support Allowance (ESA) and Incapacity Benefit (IB) claims, compared to musculoskeletal complaints.<sup>16</sup> The transition from musculoskeletal to mental and behavioural disorders is most likely explained by culturally determined changes in health beliefs and expectations.<sup>16</sup> Societal beliefs must be understood and taken into account when designing policies, with important implications for policies designed to prevent and reduce mental illness in the workplace.

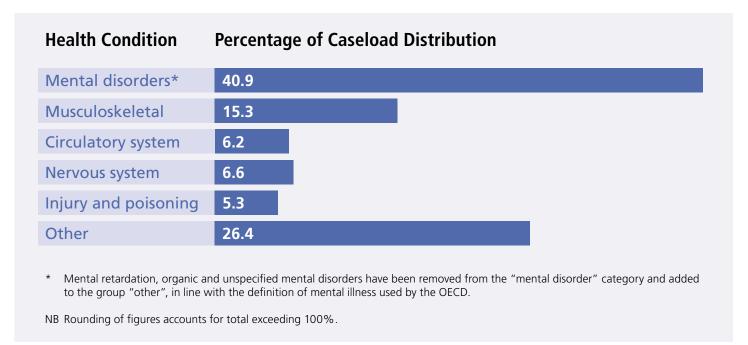
#### **Benefits**

In 2013, some 40.9% of ESA recipients had 'mental and behavioural disorders' as their primary condition.1 However, the true impact of mental illness on sickness and unemployment benefits is almost certainly underestimated in routinely collected data. Many people receiving ESA/IB are undergoing a Work Capability Assessment; 2013 data suggest that 40% are found 'fit for work'18 and invited to claim Jobseeker's Allowance where health data are not recorded. The Organisation for Economic Co-operation and Development (OECD) has highlighted the level of psychiatric morbidity in this population.<sup>4</sup> Co-morbidity between physical and mental health conditions is common.<sup>19</sup> The longer any period of sick leave extends, the greater the risk of mental illness being a factor, 20 either as an initial unrecognised comorbidity or as a secondary maintaining factor. Knudsen has shown that those with depression have over three times the risk of receiving disability benefits, even when all those categorised as 'mental illness' are excluded from the analysis.21

#### **Presenteeism**

Counter-intuitively, many of those with mental illness fail to take sick leave when they need it.<sup>22,23</sup> This is often ascribed to their concerns about stigma.<sup>24</sup> However, untreated mental illness reduces productivity, and this represents the biggest single contribution to the economic losses due to mental illness.<sup>25</sup> OECD evidence suggests that common mental disorders reduce productivity as much as severe mental illness.<sup>4,22,23</sup> There is an association between presenteeism and longer sick leave, <sup>4,26</sup> perhaps because by the time these workers take sick leave, they are more ill and therefore take longer to recover.

Figure 10.1 Caseload distribution by health condition in February 2013 (as a share of all Employment and Support Allowance recipients)



Note: Mental retardation, organic and unspecified mental disorders have been removed from the "mental disorder" category and added to the group "other", in line with the definition of mental illness used by the OECD.

Source adapted from OECD (2014), Mental Health and Work: United Kingdom (data from Figure 2.1)

#### The individual

Some 60–70% of people with common mental disorders are in work.<sup>4</sup> Mental illness may best be viewed as a risk factor that combines with others in a way that may lead to employment difficulties (though the reverse is also true – employment difficulties can contribute to mental illness). Mental illness often begins at an early age, and many disorders are recurrent over the course of an individual's life.<sup>27</sup> Many of those on sick leave due to mental illness are young people aged 16–24 who have never had a job or paid National Insurance contributions.<sup>4</sup> This has devastating consequences, as distance from the labour market at this age has a long-term impact on employability and lifetime earnings.<sup>28</sup>

The relationship between mental illness and employment at the end of working life is complex and there has been little research in this area. Mental illness is a major driver for premature departure from the labour market, often in the form of illness retirement.<sup>29,30</sup> Common mental disorders may be the factor that tips workers with physical health conditions into retirement.<sup>31</sup>

Co-morbidity of mental disorder with physical disorders is very common,<sup>4,19,32</sup> but under-recognised. In England, 15 million people have a long-term condition such as arthritis or coronary heart disease. Of these, 30% also have mental illness, most often depression or anxiety. For every £8 spent on such long-term conditions, £1 is linked to patients' poor mental health. Of the 10 million people with mental illness in England, 46% also have a long-term physical health problem.<sup>19</sup> The interaction between the two

groups of disorders can be complex – having a long-term physical health problem is a risk factor for mental illness, but the reverse is also true. Some share risk factors such as adverse early life experience. Recognition of one disorder in the presence of another presents clinical challenges, as many symptoms such as poor sleep, fatigue or weight loss can be attributed to either condition, and psychological distress may be thought 'understandable'.

Mental/physical co-morbidity rises with age<sup>34</sup> and is more strongly associated in the least financially well off. Mental illness in the context of poor physical health responds more slowly to interventions in those in lower employment grades,<sup>35</sup> further contributing to the generation and maintenance of social inequalities in health.<sup>19</sup> Moreover, mental/physical co-morbidity is a key risk factor for premature exit from the labour market.<sup>36,37</sup>

People in employment with mental illness, particularly if they have a low educational attainment level, are often in jobs with lower pay, poorer management, and with greater job insecurity than individuals with good mental health. 38,39 Workers in low-skilled jobs are more likely to report job strain, and job strain increases the risk of mental illness. 10,40 Low-skilled workers are often on short-term or temporary contracts, but job insecurity is itself associated with a 33% greater risk of common mental disorders. 10

Early life risk factors identifiable before an individual enters the labour market play a strong role in the likelihood of future employment. Childhood temperament, cognitive ability, educational attainment and self-rated health predict later receipt of disability benefits.<sup>39,41,42</sup>

#### The family

Poor occupational outcomes can magnify the adversity associated with mental illness, and this can extend to partners, children and family. As Exiting the labour market negatively impacts on self-esteem and identity. The associated financial impact adversely affects those who depend on that person's income. Mental illness and the impact on health behaviours such as alcohol consumption also contribute. Ar Parental unemployment has been shown to be a risk factor for poor health outcomes in children. As Although controversial, Several studies suggest that parental worklessness can be a risk factor for future employment difficulties. Shared exposures such as a difficult local labour market must, though, be taken into account.

#### The impact of work on health

The statement 'Work is good for you' is now used regularly, and there is evidence to support it as a general statement of principle.<sup>14</sup> It represents a significant and positive culture shift. It has been necessary as a counterweight to the 'work stress' movement, which is based on the premise that work makes you (psychiatrically) ill; while true for a minority, this is largely overstated.

Although many people claim that they have mental illness that has been caused or made worse by work, there are a number of reasons to be cautious about such assertions. Goodwin has shown that 'occupational' studies report higher levels of psychological distress than population-based studies.<sup>52</sup> Wainwright and Calnan have dissected the emergence of the stress-at-work discourse, suggesting that its emergence in the public discourse relates more to individual perceptions of vulnerability than to changes in workplace practices.<sup>53</sup>

Workplaces, while dramatically safer than 50 years ago, can contribute to diseases such as the pneumoconioses. However, a number of 'epidemics' of apparently occupationally based disorders, while capturing the attention of both the working public and policy makers, have proven less well founded. In 1911, musculoskeletal symptoms among telegraphers working for the Post Office so concerned the government that a formal inquiry was carried out by the Medical Research Council.<sup>54</sup> Miner's Nystagmus caused similar levels of concern,55 not least in the run-up to the First World War. Both disorders saw the number of apparent sufferers rocket after they were declared compensable diseases; both consisted of non-specific symptoms and signs that were open to a variety of interpretations. Both have subsequently disappeared both from public discourse and from medical textbooks. Culpin, pre-eminently, understood their emergence and their relationship with individual risk factors, but his significant contribution has now been largely forgotten. 56,57,58 These examples serve as reminders that caution is required when considering 'new' disorders, balancing this against our knowledge that workplaces can indeed contribute to, or even be the primary driver of, serious disorders.

Part of the difficulty with the 'Work is good for you' statement is that it is too simple. What work? For whom? When? In what way? The statement has been amended – 'Good work is good for your health'4,14 – but there has been very little objective research on what might constitute 'good work'. The evidence base for what constitutes 'bad work' is better. The 'job strain' or 'demand-control' model contrasts the demands of the job with the decision latitude given to the employee.<sup>59</sup> Job strain describes the combination of high demands with low control. Effort–reward imbalance suggests that bad jobs are those where high effort is combined with low rewards, in terms not only of salary but also of job satisfaction and sense of achievement. 60 Stansfeld and Candy concluded in their meta-analysis that both effortreward imbalance and high-strain jobs were prospectively associated with worse mental health.<sup>10</sup> It remains unclear though whether studies using objective (rather than subjective) reports find the same results, 20,61,62 and the extent to which the findings remain robust when risk factors from earlier in life are included in analyses.<sup>42</sup> Kivimaki has added organisational justice, which incorporates both the way in which decisions are made in an organisation ('procedural element') and the way in which individual employees are treated ('relational component').63 This model independently predicts both poorer mental health and greater sickness absence.64

Shift work has a small association with obesity and cardiovascular disease, but the evidence of a causal link with mental illness is weak. An association between long working hours and subsequent depression has been suggested in data on Whitehall civil servants, <sup>65,66</sup> although a Japanese systematic review was much less persuasive. <sup>67</sup> Stansfeld examined data from the Psychiatric Morbidity Study <sup>68</sup> and demonstrated that while some occupations were associated with greater levels of mental illness than others, there was no consistent theme, such as 'long hours', 'contact with the general public' or 'shift work', that linked them. <sup>69</sup>

#### Worklessness

Any discussion about the relationship between work and mental illness is incomplete without recognition of the importance of the association between worklessness and mental illness. The most commonly used definition of worklessness in the UK includes those unemployed, those out of work for health reasons and lone parents.<sup>70</sup>

As with sickness absence, mental illness is both a risk factor for worklessness and an outcome of it. Individuals can get trapped in a cycle where their mental illness creates and maintains their worklessness, which in turn worsens their mental health. One form of worklessness, unemployment, is associated with an initial worsening of mental health, possibly followed by a period of adjustment but with a further worsening after that.<sup>71</sup> Suicide rates are greater in the unemployed than the employed by at least a factor of two;<sup>72,73</sup> self-harm is up to 10 times higher.<sup>74</sup>

The recession that began in 2008 has focused particular attention on this area.<sup>75,76</sup> Perceived job insecurity has risen, and job insecurity is associated with depression.<sup>43</sup> The gap in employment rates between those with and without mental illness<sup>4</sup> has increased by over 10%,<sup>75</sup> particularly in males and those with low educational attainment; the unemployment rate for those with a moderate disorder is double the overall rate and four times the overall rate for those with severe mental illness.<sup>1</sup> There was a greater increase in vulnerability to unemployment in countries with more stigmatising attitudes to mental illness.<sup>75</sup> This is worrisome, when surveys suggest that the public may feel that mental health services are low priority when faced with fiscal restraints.<sup>77</sup>

Recessions widen income inequalities, which are, in turn, associated with mental illness. Higher personal debt is associated with a higher risk of a range of mental disorders. Social inequalities widen and economic stress can impact on families, with implications played out over decades. The World Health Organization (WHO) suggests that adverse impact on mental illness in the recession is avoidable. Lunau has demonstrated that, in Europe, protective labour market and social policies buffer the effect of an adverse psychosocial environment on depression.

## The role of the workplace in minimising the burden of mental illness

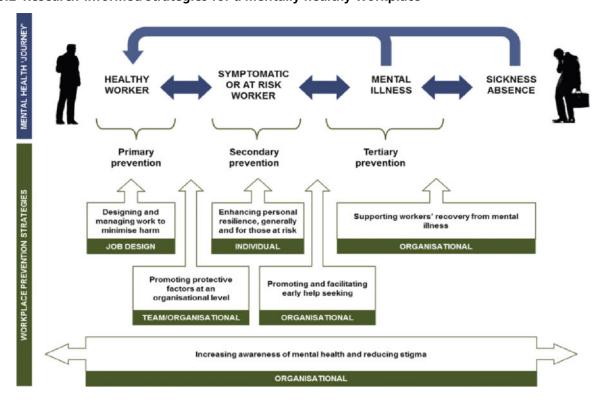
Strategies in the workplace to prevent mental illness have been divided into organisational and individual level

interventions. Evaluation of these has been disappointing; most result in small improvements compared with the investment required to implement them.<sup>85,86</sup> Far better is to consider an integrated model, such as that proposed by Henderson and Harvey (see Figure 10.2).<sup>87</sup>

When designing preventative strategies, focusing on harmful 'stresses' in the workplace risks modifying expectations in a way that perversely leads to an increase in illness reporting. It is better to promote ways in which well-designed work can lead to psychological benefits. Systematic reviews have shown that measures that increase control, such as allowing employees flexibility in their working hours (within the confines of the business need), are simple to implement, and improve workers' mental health.88,89 Work-life policies, such as parental leave and flexibility for childcare, symbolise a concern for employees and their families, thereby creating a sense that the organisation is supportive of employee needs. Managers have a pivotal role in maintaining staff welfare. Early and regular contact from managers during a sick leave is associated with a more rapid return to work,90 but few managers feel confident to do this.

As with physical illness, workers with mental illness do not need to be fully recovered to return to work. The longer an individual is away from work, the more difficult it is for them to return.<sup>14</sup> This may be further complicated by a worker experiencing increased anxiety around the return-to-work process. Temporary adjustments, such as part-time working, altered work hours and altered job content, facilitate employees returning to the workplace and may play a crucial role in recovery.

Figure 10.2 Research-informed strategies for a mentally healthy workplace



Source 'Developing a mentally healthy workplace: A review of the literature', Harvey S, Joyce S, Tan L, et al. Sydney, 2014.

The low rates of employment among those with psychotic illnesses are substantially due to the multiple barriers preventing entry to, and retention in, work. Such individuals are more likely to underachieve in education, less likely to find employment, less likely to be promoted and more likely to leave the workforce early. Recognition and treatment are improving, but the exclusion of these individuals from the workforce has costly consequences – for themselves, their families and the economy. Individuals with psychotic disorders such as schizophrenia and bipolar affective disorder can be valuable and reliable workers.93 Success in employing people with psychotic illnesses has been achieved via Individual Placement and Support schemes, which have been shown to achieve employment rates of 50-60%. 94,95,96,97 Individual Placement and Support schemes focus on finding early employment for those with severe mental illness and then provide individual support within a job.98

#### Well-being at work

There are many varied definitions of well-being, but at their core is a subjective report of how people feel and how they evaluate their lives. Three discrete aspects are recognised.

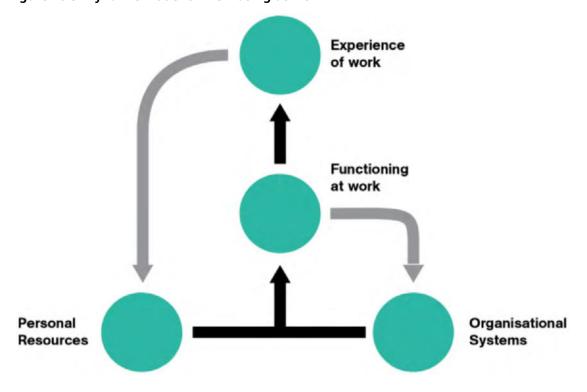
- The **hedonic** aspect refers to people's feelings or emotions, such as happiness and anxiety.
- The **eudaimonic** aspect refers to an individual experiencing a sense of competence or meaning and purpose in their life.
- The **evaluative** aspect refers to the way that people evaluate their lives; at work this is often captured using job satisfaction measures.

The model in Figure 10.3 illustrates that people's experience of work (how they feel) is influenced by how they are functioning at work (what they do).<sup>99</sup> This in turn is dependent on both the organisational systems they work in and their personal resources (who they are). The curved arrows illustrate the feedback loops in the model.

Current evidence indicates that better psychological well-being of workers is associated with reduced sickness absence, higher productivity and, in the NHS, with lower staff turnover and higher patient satisfaction. All of these studies are cross-sectional in design, however, and there is an absence of evidence from intervention studies to support the implementation of initiatives to improve the well-being of employees while at work.

A recently published, comprehensive report on well-being at work<sup>99</sup> makes wide-ranging recommendations on how organisations could improve employee well-being. These include: creating jobs that are fairly paid; providing workers with job security; ensuring that jobs have a defined role; ensuring that managers show respect for staff welfare. Most of these recommendations would already be considered good employer practice. Others, such as ensuring that the workplace is physically safe are enshrined in the Health and Safety at Work etc Act 1974,104 and recommending that organisations develop plans or policies to encourage and support employees to be more physically active is already a key component of National Institute for Health and Clinical (now Care) Excellence (NICE) public health guidance: Promoting physical activity in the workplace. 105 The recommendation that employees should have a sense of control over their own workload and have good working

Figure 10.3 Dynamic model of well-being at work



Source adapted from Jeffrey J, Abdallah S, Michaelson J. Well-being at Work. New Economics Foundation. 2014.

relationships are also factors that have been shown to prevent mental illness at work.

While it is laudable for employers to maintain or improve their employees' well-being at work, these initiatives are likely to have little impact on those whose personal resources are low due to mental illness or domestic insecurity. These groups of individuals are also more likely to work for smaller organisations, where job security and pay may be low and managers less highly trained. Before commencing well-being initiatives, all employers should first ensure that they are complying with current health and safety legislation and NICE public health guidance.

Recent recognition of the importance of well-being, while welcome, needs to be seen in the broader concept of mental health and work. Therefore, any activities aimed at promoting well-being at work should be co-ordinated through the organisation's mental health policy or plan.<sup>106</sup> Policy makers should appreciate that research is at an early stage, with few longitudinal studies, and generalisability to smaller organisations has yet to be clearly demonstrated. High-quality intervention studies are awaited. Without these, there is a risk that employees who already have the advantages of large organisations and well-trained managers gain even more benefits, while those in lower-quality jobs (including a disproportionate number of people with poor mental health, low educational attainment and low income) are not even provided with minimally safe working conditions.

#### The role of healthcare

#### **Primary care**

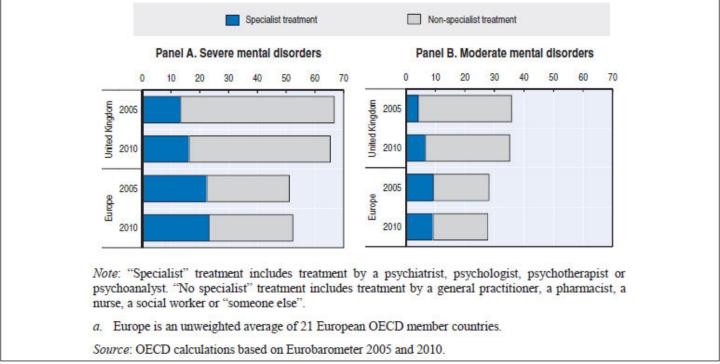
In England, most Statements of Fitness for Work ('Fit Notes') are issued by GPs. Similarly, most mental illness is managed by GPs, and GPs are the default source of most occupational health advice. While these three roles may be complementary, they also place a huge burden on GPs, who may be placed in a situation where they may feel that their responsibility to their patient is at odds with their broader public health responsibility.

Correct identification and diagnosis of common mental disorders is not simple.<sup>13</sup> Mitchell, in a high-quality systematic review and meta-analysis, showed that GPs are able to accurately exclude depression in 80% of cases but only diagnose about half the 'true' cases they see. 107 Of course, many depressed patients do not fully disclose their distress in the short time they have with the doctor. More accurate diagnoses are made by more experienced doctors, and where the patient has been seen more than once. Many GPs have no specialist training in psychiatry and most have no training in occupational medicine. Recent attempts by the Department for Work and Pensions to provide enhanced training for GPs about occupational health, and how to get the most from the Fit Note, are to be welcomed. Improved support for GPs may soon be available. A new Health and Work Service will be rolled out in the final guarter of 2014, and an evaluation will follow. The service will provide for patients who have been off work for 4 weeks to be assessed by an occupational

Figure 10.4 Share of people who sought treatment for their mental illness in the past twelve months, by severity of the illness and type of treatment, United Kingdom versus EU-21a, 2005 and 2010

Specialist treatment

Non-specialist treatment



Source OECD (2014), Mental Health and Work: United Kingdom (Figure 4.1)

health professional, who will examine the issues preventing return to work. Advice for patients, GPs and employers will be available. Take-up of recommended medical interventions will attract a tax exemption for the employer.

#### Secondary mental health services

Most mental illness comprises common mental disorders such as depression and anxiety, and yet mental health services for some time have been focused, almost to the point of exclusion, on psychotic illness such as schizophrenia.<sup>4</sup> Care for these patients has improved but the somewhat unbalanced approach to other mental illness has led to a number of unintended consequences.<sup>108</sup> GPs and other non-psychiatrists (including occupational physicians) find it hard to access specialist support for hard-to-treat patients with non-psychotic illness.<sup>14</sup>

One service that has been developed predominantly for patients with common mental disorders is IAPT (Improving Access to Psychological Therapies).<sup>109</sup> This began in 2006 and was extended in 2010 and again in 2011. In 2012, it reported on its first 1 million patients.<sup>110</sup> Uptake has been strong but the occupational outcomes have been questionable. In 3 years, only 45,000 people have moved off benefits. It is not known how many have moved into employment. The ability of IAPT to successfully manage clients back to work remains to be demonstrated.<sup>13</sup>

Many common mental disorders are not diagnosed, those diagnosed are not treated, and those treated are often under-treated or treated only with antidepressant medication when a combination of pharmacological and psychological interventions may be more helpful.<sup>4,107</sup> This is iniquitous in its own right, even before the adverse individual and family-level consequences, particularly in the current economic climate, are considered. We would argue that, given all that is known about the close association between health and work, if an individual moves out of work, or is at risk of moving out of work as a result of mental illness, this should be classified as 'severe' and should trigger the deployment of additional input. The current binary distinction between the so-called 'severe' mental illnesses and common mental disorders like depression and anxiety is not sustainable. 'Severe' and 'mildto-moderate' as currently used are redundant and, in reality, based almost solely on diagnosis rather than functional impairment. So-called 'mild' disorders can produce adverse occupational outcomes.

Occupational medicine remains a small and underfunded specialty; less than 30% of the UK workforce has access to an occupational physician.<sup>5</sup> Occupational health practitioners are increasingly required to manage patients with common mental disorders and medically unexplained symptoms and syndromes.<sup>111</sup> The new curriculum for specialist occupational medicine training places much greater emphasis on an understanding of mental illness although, as with primary care, there is an issue regarding the availability of hands-on training in the assessment and management of common mental disorders. OECD data highlight that improved

employment and occupational outcomes are achieved when specialist advice is available.<sup>4</sup> Psychiatrists and occupational physicians working together are able to successfully manage patients at risk of falling out of work, but who have not been helped either by primary care or secondary care psychiatry.<sup>112</sup>

Mental illness and poor occupational outcomes share a number of individual and workplace risk factors, can each generate a range of additional risk factors for the other, and can therefore be seen as setting a trap for those unfortunate enough to experience one or other. Individually, but especially in combination, mental illness and poor occupational outcomes are powerful contributors to a range of health and social inequalities. The relationship between the two is complex, extends across the life course and is mutually reinforcing. Choice explains little or nothing. Simple changes to health, economic, employment or benefit policies alone, which fail to take into account the clustering of disadvantages, will do little to address the problem.

### Note on NEETs (young people 'not in employment, education or training')

Young people who are 'not in employment, education or training' – the so-called NEETs – epitomise much of what has been described in this chapter. At the end of 2013, over 1 million young people in the UK aged 16–24 (14.4% of this group) were NEETs.<sup>114</sup> Even though the number of 18–24 year olds remaining in education has been rising since 2008, the sharper decline in the numbers in employment has led to a rise in the proportion of 18–24 year olds who are NEETs.<sup>114</sup>

The NEET population is heterogeneous.<sup>115</sup> A proportion are only transiently not in employment, education or training; but over half are not in employment, education or training for more than 12 months.<sup>114,116</sup> Around 50% are unemployed and actively looking for work, but this means that the same number are distanced from the labour market by illness or caring responsibilities such as parenthood.<sup>114</sup> Some become NEETs immediately they leave school, while others fall out of initially promising work or educational opportunities.<sup>116</sup>

Many of the risks for poor occupational outcomes mentioned in the chapter apply to NEETs – disadvantaged backgrounds (low-income households, families where neither parent works), low educational attainment, 114 drug and alcohol misuse, poor physical and mental health. 114 The recognition that these multiple disadvantages cluster together is of fundamental importance to understanding the difficulties they face.

The recession has been disproportionately hard on young people<sup>115</sup> and this has expanded the numbers who may have to deal with the longer-term implications of having been NEETs. Wage scarring<sup>117</sup> (the deterioration of wage prospects stemming directly from an initial spell of unemployment), reduced likelihood of later employment,<sup>115</sup> and higher crime participation<sup>118</sup> have all been linked. Each impacts adversely on wider society as well as on the individual.<sup>116</sup>

#### Author's suggestions for policy

- Employment status should be a routine and frequently updated part of all patients' medical records. This will provide the baseline data for employment status to be an outcome of all medical specialties, including primary care.
- Employers should avoid undertaking stress audits, as these risk modifying expectations of employees and lead to an increase in reports of mental illness. Rather, preventative strategies in the workplace should focus on promoting well-designed work.
- Managers should be trained to understand how mental illness might present in the workplace and to understand their role in facilitating retention of employees with mental illness in the workplace.
- Individuals who risk falling out of work due to mental illness should be prioritised to receive an urgent assessment by secondary psychiatric services.
- Commissioners need to steer secondary psychiatric services towards a model based more on functional impairment than on diagnostic category. Alternatively, a new psychiatric discipline could be encouraged ('primary care psychiatry') or liaison psychiatry (which manages the interface between physical and mental health and already has a focus on improving overall function) should be further expanded out of secondary and into primary care. <sup>113</sup>
- The numbers of doctors being recruited into occupational medicine should be expanded. Reciprocal training opportunities with psychiatrists are needed.
- The health status of those claiming Jobseeker's Allowance should be assessed, recorded and monitored. Those with evidence of mental illness should be signposted to local services. Alternatively, medical services and in particular psychiatric services could in-reach to Jobcentre Plus, as they currently do to the criminal justice system.
- The employment rate of patients with schizophrenia or bipolar affective disorder is unacceptably low. Along with widening the availability of Individual Placement and Support services, more needs to be done to improve the access of this patient group to the labour market.

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## Special case study – mental illness and health professionals

### Case study author

Clare Gerada<sup>1</sup>

1 Medical Director, Practitioner Health Programme London

#### Introduction

The Practitioner Health Programme (PHP) is a self-referral, confidential, primary care led mental health service for doctors and dentists in the London area. It has been operating since 2008. Data from this service are used to illustrate the problems facing health practitioners in accessing mental health services and why services such as the PHP meet a much needed gap in service provision.

#### Extent of the problem

Doctors have high rates of anxiety<sup>1,2</sup> and depression relative to the general population.<sup>3,4</sup> In the UK, between 10% and 20% of doctors become depressed at some point in their career.<sup>5,6</sup>

Young female doctors are more likely to develop mental illness than their male counterparts. In a large Australian survey of medical students and doctors, female doctors reported higher rates than male doctors of current psychological distress (4.1% versus 2.8%), high likelihood of minor psychiatric disorders (33.5% versus 23.2%), and current diagnoses of specific mental health disorders (8.1% versus 5.0% for depression; 5.1% versus 2.9% for anxiety).<sup>7</sup>

Suicide is a disproportionate cause of death among doctors,<sup>8</sup> relative to the general population.<sup>9,10</sup> Female doctors have a 3.7-fold to 4.5-fold increase of death from suicide compared with females in the general population and male doctors a 1.5-fold to 3.8-fold increase, compared with males in the general population.<sup>11,12</sup> In the general population, men account for three-quarters of successful suicides.<sup>13</sup> Studies on UK cohorts found that suicide is twice as common in female doctors as among women in the general population.<sup>8</sup>

Despite these high rates of mental illness, doctors lack access to confidential, timely and appropriate mental health services that they feel able to use, and they are reluctant to come forward for help.<sup>14</sup>

These problems came together as a major contributary cause of the suicide of a young psychiatrist who, months after giving birth, killed herself and her baby daughter (see Box 10.1).<sup>15</sup>

#### Box 10.1 Dr Daksha Emson

Dr Daksha Emson, a psychiatrist, and her 3-month-old daughter died following an extended suicide (in which Dr Emson killed herself and her baby) in 2000. Daksha had a long history of severe mental health problems (bipolar disorder) but went to considerable lengths to hide her illness from her supervisors. She feared widespread stigma if her illness became known and that it would damage her career prospects.

Daksha's care fell between many gaps – and although she was cared for by an NHS consultant psychiatrist, she did not want to be referred to the local commuity mental health services, fearing that this would compromise her confidentiality.

A subsequent independent inquiry made a number of comments about contributory factors, which included:

- the stigma of mental illness
- being both a doctor and a patient
- the inadaquacies of occupational health services.

Report of an independent inquiry into the care and treatment of Dr Daksha Emson and her daughter Freya may be accessed at http://www.simplypsychiatry.co.uk/sitebuildercontent/sitebuilderfiles/deinquiryreport.pdf

## Why doctors are at risk from mental illness

There are many reasons put forward as to why doctors are at greater than background risk of developing mental health problems, which can arise from two main areas: occupational risk factors (risks associated with the job itself; this can be further divided into clinical and structural aspects of the job); and individual risk factors (personality traits and psychological vulnerabilities, which may interact with occupational risk factors to create psychological distress). These have been reviewed by Brooks et al.<sup>6</sup>

Occupational risk factors (clinical) are:

- emotional demands of working with patients
- patients' high expectations about the power of medicine putting unrealistic pressure on doctors
- aggression (both verbal and physical) from patients
- easy access to prescription drugs.

Occupational risk factors (structural) are:

- heavy workload and working hours
- long shifts and unpredictable hours
- lack of cohesive teamwork and social support

lack of 'firm' structure (i.e. teams which regularly change their members due to junior doctor shift-working patterns).

Individual risk factors are:

- personality traits of many medical professionals, such as perfectionism, can lead to individuals becoming increasingly self-critical
- unhelpful coping strategies (e.g. emotional distancing, rather than actively dealing with stressors)
- excessive sense of responsibility
- desire to please everyone
- guilt for things outside one's own control, self-doubt
- obsessive compulsive traits.

#### Barriers to care

#### Box 10.2 Case study 1 - 'Jane'

Jane was an ST3 paediatrician working in a neonatal unit. Her shifts were long and she was required to provide internal cover. She felt exhausted and found that even when off duty she couldn't sleep. She found that she couldn't eat, and thought that she was useless and to blame for the bad Care Quality Commission report her hospital had just received. She could not take time out, as she felt that this would be letting down her peers and she was frightened of talking to her consultant, as he would think her weak.

Jane began to feel that people were whispering about her and commenting what a bad doctor she was. She tried to make an appointment with her GP but was told that as she had moved address, she was no longer registered. Jane took an overdose and was found by her flatmate. She was admitted to her own hospital with psychotic depression.

#### Box 10.2 Case study 2 – 'Peter'

Peter, a 54-year-old GP who also worked in a management position, began to feel low after his marriage ended. He began to sleep badly, waking several times every night. He self-prescribed sleeping tablets and used alcohol as an additional aid to sleep – finding that at night he needed to drink more to get to sleep. Peter knew he was unwell, but his own GP was a friend and Peter didn't know what to do. Peter was stopped by the police one morning, while driving to work. He was found to be 1.5 times over the limit.

A survey of 3,512 doctors published by the Royal College of Physicians (2009) had a 70% response rate and found that only 13% of those responding would speak to a professional or governmental organisation if suffering from mental illness, and that the apparent lack of confidence in the current system protecting doctors' confidentiality may exacerbate these trends.<sup>16</sup>

An Ipsos MORI study conducted on behalf of the Department of Health (England) found that the majority of stakeholders (all health professionals) said they would fear being stigmatised or labelled, if their colleagues knew they were suffering from either an addiction (73%) or mental health problems (63%). For doctors alone, these percentages rise to 81% and 73% respectively; for doctors who are also managers these percentages rise to 84% and 74% respectively.<sup>17</sup>

It makes sense to improve the mental health care of health practitioners – not least because of the link between the health of health professionals and the safety of the patients they care for, as made clear in the report *Invisible Patients*. <sup>18</sup>

## The Practitioner Health Programme

The Practitioner Health Programme (PHP) is a service that was established following the Independent Inquiry after the death of Dr Emson (see Box 10.1). It was established to address the mental health and addiction health needs of doctors and dentists, filling a gap created by health professionals' discomfort with accessing standard NHS care in London. The service is an integrated mental health service, led by a GP incorporating a team of mental health professionals. Practitioner-patients are guarenteed confidentiality unless there are concerns for their own health or the patients they care for, or where it is a regulatory requirement to disclose.

The PHP service offers:

- information for both practitioner-patients and those close to them
- expert assessment
- both telephone and face-to-face support
- advice and treatment for mental health and addiction problems
- assistance in finding peer support
- advice to practitioner-patients' colleagues and families
- referral to specialists, where required
- support in return to work in liaison with the patient's occupational health service.

#### **Presenting problems**

Patients attending the PHP are classified into four main groups:

- addiction (drugs and/or alcohol)
- common mental illness, e.g. depression, anxiety, panic disorder, obsessive
- compulsive disorder
- complex mental illness, not involving addiction, e.g. bipolar disorder, psychosis, severe anorexia nervosa
- other, e.g. physical health problems, no diagnosis, organic presentations or unknown causes

From 2008 to 2013, the service has seen more than 1,000 practitioners mainly from London. Averaged across the 5 years, around 75% of the doctors seen have mental health problems (commonly depression, which accounted for 52% of mental health diagnoses) and 22% have problems with addiction (around two-thirds of these doctors had problems with alcohol dependence). Very few patients presented with physical health problems alone, although physical co-morbidity is common.

#### Presenting complaints for the first 5 years

Total presenting complaints	1,057
Addiction +/- co-morbidity	22%
Major mental illness	23%
Minor mental illness	52%
Other	3%

The range of drugs used by those presenting with problems included:

- street heroin
- prescribed and non-prescribed opiates
- stimulants, including cocaine, ketamine and amphetamines
- methadrone
- benzodiazepines
- addiction to over-the-counter medication.

Most doctors who were misusing drugs used pharmaceutical, rather than 'street' preparations. The specialty of the addicted doctor or dentist was often associated with their drug of dependence – for example, anesthetists were more likely to be addicted to injectable anesthetic drugs obtained via the anaesthetic room; GPs were more likely to use oral opiates such as Oramorph, morphine-slow release, dihydrocodeine; dentists used nitrous oxide, benzodiazepines; and psychiatrists disproportionately used drugs such as metamphetamines, amphetamines and mephedrone.

#### Age: sex ratio

There has been an increasing number of patients presenting to the service each year, from 195 patients in 2009 to 242 in 2013. The age of the patients presenting for care has also changed significantly: since 2009, a falling proportion of

older doctors and an increasing proportion of young doctors have self-presented.

In 2008 and 2009, some 42% of the 195 patients presenting to the service were 46 years old or older and a quarter were 25–35 years old. Between 2012 and 2013, a total of 55% of the 242 patients presenting to the service were 25–35 years old, and 22% were over 46 years old. To put these figures into perspective, under 35 year olds represent 28% of those on the General Medical Council register.

The commonest age for presentation of both sexes is 29 to 30 years old. However, the proportion of women attending the service has increased considerably since 2009, and now young women (under 35 years of age) represent the majority of the patient population, with a reduction in the proportion of older men.

#### **Specialty**

No specialty is exempt from mental health problems – although some are over-represented in particular categories at the PHP. A total of 44% of anaesthetists, 42% of dentists and 36% of emergency doctors who presented for help at the PHP did so with problems related to addiction, compared with 4% of paediatricians, 14% of foundation trainees and 17% of physicians. This trend is reversed when looking at the proportions presenting with anxiety and depression, such that 75% of paediatricians, 61% of physicians and 58% of foundation trainees presented with problems related to anxiety or depression, compared with 31% of anaesthetists, 38% of dentists and 38% of emergency medicine presentations.

#### Confidentiality and occupational health

The experience at the PHP is that fear of breach of confidentiality is the single most important barrier preventing doctors from attending care for mental health problems. The independent inquiry following the death of Dr Emson (see Box 10.1) commented that doctors were reluctant to attend occupational health services, which were widely mistrusted by those who had not used them and by many of those who had.<sup>15</sup> Doctors were unwilling to be honest about the level of their distress for fear of dismissal from their organisation.

One of the recommendations of the report was that 'the Department of Health needs to strengthen the effectiveness of Occupational Health Services in the NHS by taking responsibility for setting standards, monitoring quality in the provision of these services'. Since the report was published in 2003, the Department of Health has funded the development of evidence based guidelines in occupational health; three national occupational health audits; and, in conjunction with the Faculty of Occupational Medicine, the development of national standards for occupational health departments, known as SEQHOS (Safe Effective Quality Occupational Health Service).

Recent evidence suggests that workers' trust in their organisation's occupational health service is complex and

partially related to their relationship with their line manager and whether or not they perceive that their medical condition is affecting their work.<sup>19</sup>

**Outcomes** 

Analysis using validated tools<sup>20</sup> found that patients attending the PHP scored high levels of mental health severity and were of a comparable sample to those attending 'standard or mainstream' NHS mental health services and that, once in treatment, doctors do very well.

The PHP has been cited as an excellent example of a specialist service and as a flagship for other areas of the UK.<sup>21</sup> Detailed analysis<sup>22</sup> of the first 18 months found that of the 554 presenting:

- a total of 77% remained in, or returned to, work while a practitioner-patient
- there was a 79% abstinence rate for those treated for alcohol or drug addiction (compared with 10%–20% of those treated in the general population)
- evaluation (through a range of recognised, validated questionnaires) demonstrates improvements on all measures, including mental health, and social and work functioning.

The key strengths of the PHP have been identified as:23

- providing a service that is for practitioners, run by practitioners: specialists in treating doctors and dentists with addiction, mental health and physical health issues
- providing a clear process to recovery: focus on the main goal as facilitating practitioner recovery and re-entry into, or continuation with, work
- including all health issues: treating the whole person rather than the presenting issue
- being transparent about confidentiality: mapping out parameters and consulting with the practitioner-patient at every stage.

#### The economic case

The costs to the NHS of London doctors and dentists who fall ill are estimated at £23 million a year in terms of sick leave, suspensions and cover for everyday duties. Evidence on the costs of ill health to the NHS in London is largely restricted to doctors. It is therefore reasonable to assume that the figures below would be greater if dentists were included. It is estimated that the cost of doctors suspended on ill health grounds could amount to £5.5 million per annum across London's NHS, based on an estimated 38 doctors (out of a total of 27,640 in London<sup>24</sup>) with an associated cost of £144,000 each. <sup>25</sup> The latter cost is made up of locum cover, management costs and legal costs, but does not cover salary costs, which would be incurred whether the clinician were suspended or not.

Economic analysis of the first 3 years of the PHP has estimated that it has made net savings of £4.3 million per annum in London through reductions in absenteeism and suspensions for ill health. Scaled up (from 32,000 doctors and dentists in London to all 152,700 doctors and dentists in the NHS in England), this would suggest that ill health in doctors and dentists costs the NHS at least £110.7 million per year so, on an England-wide basis, the PHP could make savings of more than £20 million per year.<sup>26</sup> The PHP service commissioned for London residents costs around £1 million per year.

#### Conclusion

Doctors have special health needs and problems that are particular to them in accessing healthcare, especially when their needs are related to mental illness. When provided with specialist services, their health outcomes are excellent and most are able to return to work.

The worrying trend is the rise of younger doctors presenting with mental illness, and in particular young women. There appears to be a need for support and monitoring from a very early stage of the doctor's career, with medical training emphasising clear pathways for help and increasing awareness of the vulnerability of doctors to mental illness.

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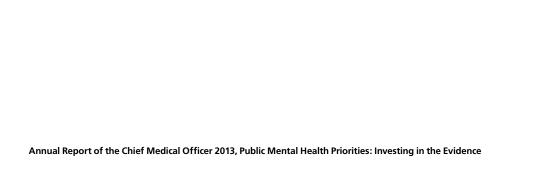
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Section 5

## Parity of esteem



## Chapter 11

# Stigma and discrimination

#### **Chapter authors**

Graham Thornicroft<sup>1</sup>, Sara Evans-Lacko<sup>2</sup>, Claire Henderson<sup>3</sup>

- 1 Professor of Community Psychiatry, King's College London, Institute of Psychiatry
- 2 Lecturer, King's College London, Institute of Psychiatry
- 3 Clinical Senior Lecturer, King's College London, Institute of Psychiatry

# **Key statistics**

- Some 87% of mental health service users across England reported experiencing discrimination in at least one aspect of life in the preceding 12 months in a survey conducted across England in 2011.<sup>1</sup>
- About 70% of mental health service users feel the need to conceal their illness (according to three studies).¹
- It is still common for mental health service users in England to report being shunned by others (an annual survey held 2008-2011¹ found that in 2008 58% of respondents reported being shunned, decreasing in 2011 to 50% of respondents).
- The most common type of newspaper article on mental illness are those that contribute to stigma, accounting for nearly half of all coverage in a sample of local and national newspapers across England between 2008 and 2011.²
- A survey of mental health service users in England in 2011¹ found that 25% reported problems with personal safety related to having a diagnosis of mental illness, including verbal or physical abuse.
- In 2003, employment in the whole adult population was about 75%; for people with physical health problems it was about 65%, while for people with long-term mental illness it was 24%.<sup>3</sup>
- In 2011, 19% of mental health service users surveyed in England reported experiencing discrimination in seeking work; 17% had experienced discrimination while in employment; and 46% reported not looking for work due to the anticipation of discrimination. ¹
- Legal analysis of cases brought to employment tribunals under the Equality Act 2010 shows that failure to make 'reasonable adjustment' is the most common type of mental health discrimination claim;<sup>4</sup> this type of claim also has the highest win rate, at 72%.
- Legal analysis of cases brought to employment appeal tribunals on the basis of mental health discrimination shows that 58% were based on an error in the application of the law/procedure; such appeals also have the highest win rate, at 60%.<sup>4</sup>
- A service user survey held each year between 2008 and 2011 in England¹ showed no significant reduction in reported discrimination from either health professionals (30% in 2008 and 29% in 2011) or mental health professionals (34% in 2008 and 30% in 2011).

# Overview

This chapter presents information to:

- define stigma and discrimination
- give evidence on their severity and impact on the lives of people with mental illness
- describe population-level and target-group-level interventions and their effects

- examine the particular detrimental effects of stigma and discrimination on healthcare, employment and citizenship
- compare progress in England with that in other comparator countries
- examine the relevant health economic evidence
- make recommendations for further stigma reduction in England.

In future, society needs to:

- operationalise the concept of 'reasonable adjustments' per the Equality Act 2010 with respect to mental illness in all areas of life, including the workplace, health and social care, education, the justice system, sports and leisure, and political participation and
- support and evaluate projects that aim to empower mental health service users to respond to stigma and discrimination, for example through addressing self-stigma, training in self-advocacy and peer support.

# Introduction

Stigma and discrimination against people with mental illness have a substantial public health impact in England which can be an important factor in maintaining inequalities,<sup>5</sup> including poor access to mental and physical healthcare; 6 reduced life expectancy;<sup>7,8</sup> exclusion from higher education<sup>9,10</sup> and employment;3 increased risk of contact with the criminal justice system; victimisation;<sup>11</sup> poverty; and homelessness. Goffman's seminal definition of stigma written in the 1960s – 'an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one' – is still relevant.12 More recent conceptualisations include labelling, stereotyping, separation, status loss and discrimination,13 and incorporate experiences of discrimination; traditionally work on stigma has tended to focus on public attitudes and knowledge about mental illnesses.

Internationally, public attitude data suggest that there has been little improvement over time;14 however, there is growing evidence of the effectiveness in high-income countries of anti-stigma interventions - both national programmes and those targeted at specific groups. As a result, many countries, including England, are investing in national anti-stigma programmes targeted at both the general public and specific target groups. 15,16 The National Institute for Health and Care Excellence emphasises the inclusion of knowledge, attitude and behavioural components when developing and evaluating behaviour change interventions.<sup>17</sup> Applying this to anti-stigma interventions requires the evaluation of lack of knowledge and misinformation such as stereotypes; prejudicial attitudes and emotional reactions such as fear and anger; and discriminatory behaviour, as evidenced by the indicators listed above and by the experiences of people with mental illness.18,19

# Key content and current issues surrounding this topic

In this chapter we focus on three areas of life in which the impact of discrimination has a significant public health impact: healthcare; employment; and citizenship. Global surveys of mental health service users, including a site in the UK, show that experiences of discrimination pervade many areas of life<sup>1,20,21</sup> and that anticipation of discrimination is even more frequent, leading people to avoid possible opportunities for employment and relationships.<sup>22</sup>

Figure 11.1 presents findings from a sample of mental health service users in England on their reported experiences of discrimination across the areas of employment, health and citizenship during 2012.

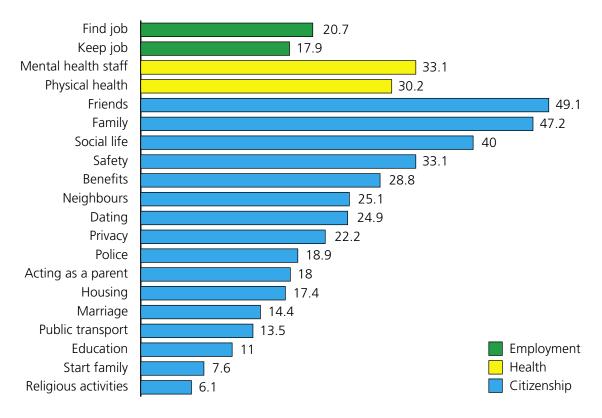
In England, Time to Change (TTC; www.time-to-change.org. uk), run by Mind and Rethink Mental Illness, is the largest ever programme to reduce stigma and discrimination against people with mental illness (see case study in Box 11.1). It is a multifaceted programme comprising national and local-level actions to engage individuals, communities and stakeholder organisations followed by a robust evaluation. Evidence from the first year of the TTC anti-stigma programme in England<sup>23</sup> showed significant improvements in life areas in which relationships are informal, i.e. family, friends and

social life. In some areas where discrimination may occur at a structural level (e.g. via regulations, laws or institutions) there were no improvements, including mental and physical healthcare and welfare benefits; in others, including those in seeking and gaining employment, early improvements have since plateaued or been lost.<sup>1</sup> This chapter therefore takes account of discrimination at both the structural<sup>24,25</sup> and the interpersonal level.

Reducing mental health-related stigma and discrimination is one of the six objectives of the Government's mental health strategy, *No Health Without Mental Health*. This was launched in 2011, the same year the Department of Health became the largest funder of the second phase of TTC (2011–2015). The Department of Health requested that TTC include campaigns targeted at children and young people, so that the programme covers all age groups.

The outcomes dashboard for monitoring progress on *No Health Without Mental Health* uses the surveys undertaken to evaluate TTC<sup>1</sup> to track progress towards its objective to reduce stigma and discrimination. The importance of reducing discrimination is reiterated in *Closing the Gap: Priorities for Essential Change in Mental Health* (Department of Health, 2014). Anti-stigma programmes are also ongoing in Wales (Time to Change Wales/Cymru) and Scotland (See Me), but not in Northern Ireland.

Figure 11.1 Prevalence of experienced discrimination among secondary mental health service users across life domains of employment, health and citizenship in England (2012)



Source Henderson et al. (In press, Social Psychiatry and Psychiatric Epidemiology.)

# Context of this topic

#### **Population-level interventions**

A review from the National Institute of Mental Health in England<sup>26</sup> identified six principles of an effective anti-stigma campaign:

- Service users and carers should be involved throughout the design, delivery, monitoring and evaluation of the campaign.
- Campaigns should be monitored and evaluated.
- National campaigns should be supported by local grassroots initiatives.
- Campaigns should address behaviour change.
- Clear, specific messages should be delivered in targeted ways to identifiable audiences.
- Long-term planning and funding should be in place to ensure campaign sustainability.

In a more recent consensus development study on effective types of messages to use in population-level campaigns, experts recommended messages which were recovery oriented, and sought to remove the distance between 'us' and 'them'.<sup>27</sup> Other research has demonstrated that enhancing public understanding of the biological correlates of mental illness is not accompanied by reduced levels of stigma.<sup>28</sup>

Several population-level programmes have shown evidence of effectiveness. Evaluation of the Nuremberg Alliance Against Depression<sup>29–31</sup> found a significant reduction in the number of suicidal acts over each of the 2 years of the campaign when compared with a control-comparison region. In Australia, survey respondents in states and territories that funded the 'beyondblue' programme<sup>32</sup> showed greater recognition of depression and more frequent recognition of depression in people they knew compared with areas which had not funded it; this may be due to greater awareness and/or greater openness on the part of those affected. In Scotland, the See Me campaign was launched in 2002. 33,34 Since then, there has been a significant reduction (30% versus 19%) in the proportion of survey respondents who agreed that people with mental illness are often dangerous, as well as a significant increase in willingness to interact with someone who has a mental illness.35 The proportion of people with a mental illness who reported experiencing discrimination also dropped significantly between 2002 and 2008.36 Survey data from 1993 to 2003 suggest that public attitudes in England worsened between 2000 and 2003, but changed less in Scotland.37

#### Interventions aimed at target groups

The three strategies most commonly used to address the stigma and discrimination related to mental illness at the individual level are:

- education (to replace preconceived myths and stereotypes with facts)
- contact (direct interactions with people who are experiencing mental illness)
- protest (to change behaviour and challenge attitudes).<sup>38</sup>

A meta-analysis of studies in 2012 revealed that, while contact was more effective than education at reducing stigma in adults, the opposite was true for adolescents;<sup>39</sup> evidence for protest is weak. The most thorough and recent systematic review is that of Corrigan et al.,<sup>39</sup> who showed that social contact interventions are more effective for adults, while educational interventions are more effective for young people.

#### **Healthcare professionals**

While anti-stigma interventions with healthcare students may have a positive short-term impact, 40 there is no evidence for longer-term behavioural change, either from targeted interventions aimed at medical students<sup>41</sup> or from the overall evaluation of TTC.1 The latter has shown no significant reduction in reported discrimination by mental health service users from either health professionals (defined as those providing primary care), hospitals, including emergency care and dental care (30% in 2008 and 29% in 2011), or mental health professionals (34% in 2008 and 30% in 2011). The TTC social marketing campaign may be ineffective among health professionals, for example because they do not recognise their role as stigmatisers<sup>42</sup> or because the 'clinical fallacy' means their attitudes and behaviour are resistant to change, as they most often see cases with the worst course and outcome. Medical students exposed to this bias during training may not benefit from anti-stigma training. Thus, initial treatment-seeking for mental illness may increase if public attitudes and behaviours improve, but negative experiences at the hands of health professionals may deter people from seeking further help.

#### **Employment**

A significant improvement in employment-related attitudes (a significant reduction in the proportion of employers who endorsed the view that people with mental health problems are less reliable than other employees and that employees with mental illness are unlikely to ever fully recover) was observed between 2006 and 2010.43 Employers also report use of workplace accommodations for people with mental health problems with increasing frequency, and these can be important for facilitating openness and disclosure by employees.44 In England there was an initial improvement after the start of TTC in terms of frequency at which mental health service users reported unfair treatment in both finding and keeping work,<sup>45</sup> but the magnitude of this change was no longer significant by 2011.1 This may be due to economic problems; European data<sup>46</sup> suggest that the gap in unemployment rates between individuals with and without mental illness significantly widened between 2006 and 2010 and that the disadvantage faced by people with mental illness was greater in countries with higher levels of stigmatising attitudes.

#### Citizenship

The 2013 Mental Health (Discrimination) Act removed sections from several pieces of legislation and abolished any common law rule which had disqualified people on the grounds of mental ill health from a number of offices and roles: Members of Parliament and membership of devolved bodies; jurors; and company directors. Exclusion from jury service is now based on being currently detained under the Mental Health Act or residing in hospital. This legislation sends an important message: that no one should be automatically excluded from playing their part as a UK citizen due to having, or having had, a mental illness. However, there is no evidence from the Viewpoint Survey in England that the ability to take part in any area of life besides contact with friends, family and neighbours<sup>1</sup> got any easier between 2008 and 2011. Apart from employment and healthcare, examples where no change in unfair treatment has been observed include welfare benefits, personal safety and parenting.

Such 'unfair treatment' covers a range of experiences in these different life areas. 47 In the area of welfare benefits. unfair treatment can include the behaviour of Jobcentre Plus staff and problems getting entitlements. Discriminatory experiences in terms of personal safety encompass disability hate crime and victimisation. A review<sup>48</sup> found that 2–13% of outpatient attenders with mental illness had perpetrated acts of violence in the previous 6 months to 3 years, while 20-34% had been the victims of violence (see also Chapter 14 of this report, 'Violence and mental illness'). The authors conclude that victimisation is a greater public health problem than perpetration, and focusing on perpetration may contribute to negative stereotypes. In the area of parenting, the problems most commonly reported by mental health service users in England are being assumed to be an unfit parent and a lack of understanding of how their mental illness could affect their parenting role.<sup>49</sup>

# Identifying and using the best data, case studies, international comparisons and economic modelling

#### Trends in public stigma in England

#### Public stigma in relation to employment

The majority of the public agree that most people with 'mental health problems want to work and that they have equal rights to employment'.\* This trend seems to have been improving slightly in recent years; however, more than 30% of the population still appear to question these statements (see Figure 11.2).

#### Public stigma in relation to mental health

Figure 11.3 suggests that there is a high level of agreement that medication and psychotherapy are effective treatments for mental health problems and that spending on mental health services is not a waste of money; however, there was not much change in public views in relation to these statements. While agreement with these statements may be associated with increased likelihood of help-seeking for mental health problems and confidence in services, they may not directly translate to greater inclusion of people with mental health problems in other contexts (i.e. employment and citizenship).<sup>5,6</sup>

#### Public stigma in relation to citizenship

The trends presented in Figure 11.4 regarding public views of people with mental illness in relation to citizenship also seem to have been improving in recent years. Although a clear majority responded positively about living next door to someone who has been mentally ill, indicators were less positive in relation to marriage and holding public office. In 2013, only a half to two-thirds of respondents gave a positive (non-stigmatising) response to including people with mental illness in public office or when considering marriage.

<sup>\*</sup> The statement 'People with mental health problems should have the same rights to a job as anyone else' could be interpreted simply as having the same rights to a job as anyone else or, alternatively, that people with mental health problems should be afforded equal rights to employment with or without reasonable accommodation.

100 90 80 Most people with mental health Percentage 70 problems want to have paid 60 employment People with mental 50 health problems should have the same 40 rights to a job as anyone else 30 -2003 2004 2005 2006 2007 2008 2009 2010 2011 2012 2013

Figure 11.2 Trends in public stigma in relation to employment

Source Department of Health, Attitudes to Mental Illness Survey. (No data were collected from 2004 to 2006.)

Year

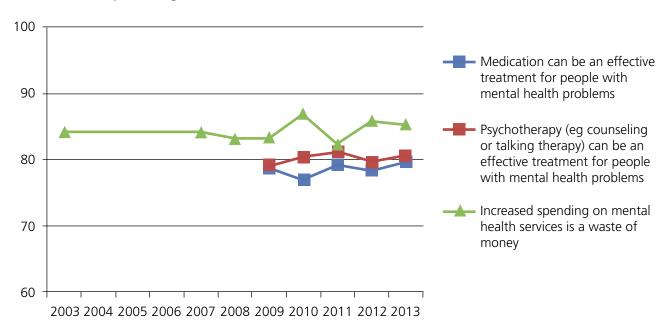


Figure 11.3 Trends in public stigma in relation to mental health

Note: all items are coded so that a trend going up indicates a favourable direction and decreasing stigma *Source* Department of Health, Attitudes to Mental Illness Survey. No data were collected from 2004 to 2006.

Anyone with a history of mental problems should be excluded from taking public office

I would not want to live next door to someone who has been mentally ill

Figure 11.4 Trends in public stigma in relation to citizenship

Note: all items are coded so that a trend going up indicates a favourable direction and decreasing stigma Source Department of Health, Attitudes to Mental Illness Survey. No data were collected from 2004 to 2006.

2003 2004 2005 2006 2007 2008 2009 2010 2011 2012 2013

#### Case studies

The case studies presented in this chapter provide examples of what can be done to reduce stigma and discrimination at national level (see Box 11.1) and what can be done to reduce the impact of discrimination and promote social inclusion (in this case) in the field of employment (see Box 11.2).

#### Box 11.1 Case study: Time To Change

The Time To Change (TTC) programme addresses mental health-related stigma and discrimination in England, and its impact on people with mental health problems and their supporters.

Phase 1 of TTC (2007–2011) consisted of a several interventions, including a social marketing campaign; programmes aimed at specific target groups, including medical students and trainee teachers and employers; local anti-discrimination initiatives; exercise programmes for people with mental health problems to promote social contact; social contact events organised by a range of stakeholders; and the use of social media such as Twitter and Facebook.

Phase 2 (2011–2015) has so far built on the experience and evidence from phase 1. Findings from phase 1 showed that, across England, there were significant improvements in intended behaviour and a positive (but non-significant) trend in attitudes towards mental illness;50 cumulative data, including the first survey from phase 2, show further improvements such that the changes in both attitudes and intended behaviour are significant. 51 There was a significant (3%) increase in the proportion of service users who reported having experienced no discrimination during the previous year, and a reduction in the median number of life areas in which discrimination was reported, from five to four.<sup>52</sup> An improvement in employment-related attitudes (indicated by a significant reduction in the proportion of employers endorsing the view that people with mental illness are less reliable than other employees and that employees with mental health problems are unlikely to ever fully recover) was observed among senior employers between 2006 and 2010.<sup>43</sup> Analysis of a sample of newspaper coverage showed 10% proportional increases in articles coded as anti-stigmatising and in the use of people with experience of mental health problems as sources, as well as a significant increase in the use of mental health charities as sources.2

The TTC programme is innovative in terms of its long-term approach; its use of evidence-based methods and its significant investment in rigorous evaluation; its use of social media both to amplify its message and to empower people to tackle stigma; and its involvement of people with lived experience at every level of both programme delivery and evaluation.

The projected long-term benefits are improved quality of life for people with mental illness and increased social capital as a result of better access to employment and services such as healthcare.

#### **Evaluation**

The evaluation comprises:

- annual surveys of the views of the general public, to assess mental health-related knowledge, attitudes and intended behaviour; and of mental health service users, to assess experienced discrimination, responses to anticipated discrimination, perceived stigma, stigma coping responses, and social capital
- content analysis of newspaper reporting on mental illness
- awareness of each burst of the social marketing campaign; associations between campaign awareness and mental health-related knowledge, attitudes and intended behaviour; and pre- and post-burst changes in these outcomes in the target population (aged 25–45 in middle income groups).

Economic evaluation comprises:

- cost of discrimination
- costs of the campaign per point change in mental health-related knowledge, attitudes and intended behaviour
- return on investment.

Information kindly supplied by Sue Baker, Director of Time To Change

#### Box 11.2 Case study: Marks and Spencer's 'Marks and Start' programme

The 'Marks and Start' programme addresses the need to improve employability among young people, the homeless, lone parents and those with disabilities, including people with mental illness.

Marks and Spencer works with four partners in their employability programmes 'Marks and Start' and 'Make Your Mark':

- The Prince's Trust: www.princes-trust.org.uk
- Remploy: www.remploy.co.uk
- Business in the Community: www.bitc.org.uk
- Gingerbread: www.gingerbread.org.uk

The partners provide coaching to improve confidence and soft skills, and where necessary give financial advice. Remploy runs the contract for the 'Access to Work' mental health programme, offering support for people with mental health problems by trained vocational rehabilitation consultants. Following pre-placement training with Remploy, participants spend 2–4 weeks on an unpaid work placement in a Marks and Spencer store paired with a buddy for everyday support. Remploy then provides follow-up support to discuss next steps and interview techniques, and to tailor CVs.

During the financial year 2012/13 Marks and Start supported 102 people with mental health conditions; 60% gained employment (42 with Marks and Spencer and 19 with other employers). By the end of January 2014 the programme had supported more than 180 people with mental health conditions (who account for 23% of all programme candidates). Some 43% have already gained employment (54 with Marks and Spencer and 25 with other employers).

Remploy also works to allow direct hiring by Marks and Spencer. In total, 64 people reporting mental health as their primary barrier to finding work were hired directly during 2012/13, and 125 were hired in 2013/14 (to the end of January). The long-term benefits are the reintegration of people into the labour market, which benefits the individual's health and reduces associated health and welfare costs, thereby benefitting the economy.

This programme's innovation is its accreditation process: a participant accredited by a Marks and Spencer line manager can take a vacancy in a Marks and Spencer store within 6 months of placement.

#### **Evaluation**

Quantitative data are kept on completion of placements and hiring within and outside Marks and Spencer (see above).

Qualitative examples include:

- A man who has depression who had been out of fulltime work for 13 years completed the placement and gained permanent employment at Marks and Spencer. Two months into his job he said: 'I love working here.' The store recruitment co-ordinator said: 'Patrick is a great member of the team.'
- A woman who has obsessive compulsive disorder and who now works as a customer assistant at Marks and Spencer following 9 years of unemployment said: 'Remploy understood the barriers I was experiencing ... Our greatest joint achievement was rebuilding my confidence.'

Information kindly supplied by Samantha Veasey, Head of Employee Health and Wellbeing at Marks and Spencer

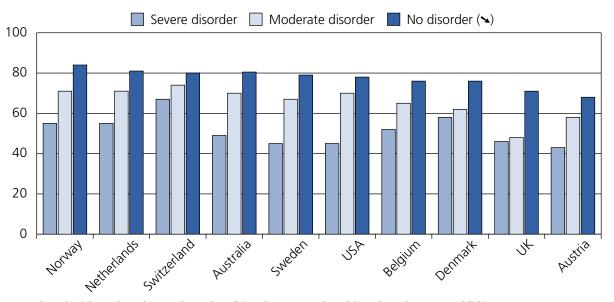
# International comparisons

In addition to experiencing higher rates of poverty and lower incomes, people with mental illness face a considerable unemployment disadvantage.<sup>53</sup> We know that the majority of people with mental illness want to work and that it is important for recovery; however, Figure 11.5 demonstrates the significant disparity in employment rates between individuals with and without mental health problems.<sup>54</sup> In the UK, although overall employment rates are relatively low compared with other high-income countries, those with both moderate and severe disorders appear to have substantially

lower rates of employment compared with those with no disorder.

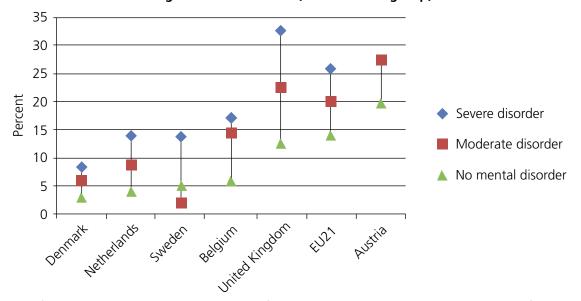
As employment rates are influenced by level of education, it is also important to investigate participation of individuals with mental illness in higher education. Figure 11.6 demonstrates that individuals with moderate and severe disorders are more likely to stop full-time education before age 15.54 Importantly, in the UK, overall rates of stopping full-time education before age 15 seem to be higher; and the disparity in rates between those with no mental disorder and those with severe mental disorder is greater than in any of the other high-income countries.

Figure 11.5 Employment rates by mental health status across 10 high-income countries



Source OECD (2012), Sick on the Job?: Myths and Realities about Mental Health and Work, OECD Publishing, http://dx.doi.org/10.1787/9789264124523-en.

Figure 11.6 Proportion of individuals who stopped full-time education before age 15, by mental health status across six high-income countries (and the EU21 group)



Note EU21 refers to all EU countries prior to the accession of the 10 candidate countries on 1 May 2004, plus the four eastern European member countries of the Organisation for Economic Co-operation and Development, namely the Czech Republic, Hungary, Poland and the Slovak Republic.

Source OECD (2012), Sick on the Job?: Myths and Realities about Mental Health and Work, OECD Publishing, http://dx.doi.org/10.1787/9789264124523-en.

# Economic modelling

Epidemiological data demonstrate the adverse consequences for individuals with mental illness in terms of education and employment; however, there are limited data available on the economic costs of stigma. The economic evaluation of TTC builds on an evaluation of the See Me campaign, examining the cost of the campaign in relation to the estimated number of people in the population with improved stigma outcomes.<sup>55</sup>

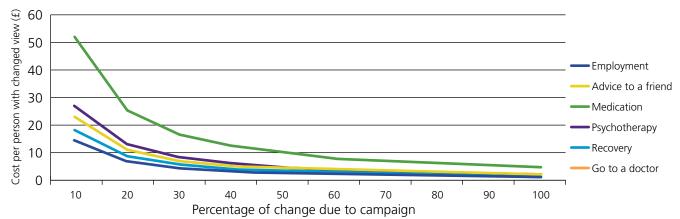
Figures 11.7, 11.8 and 11.9 show that, based on average social marketing campaign costs associated with TTC, and assuming that the campaign was only responsible for 50% of the difference in responses among those who were aware versus those who were not aware of the TTC campaign, the cost of change in **knowledge** would be between £2.95 and £8.56 per person. The cost of a change in **attitudes** would range from £2.50 to £10.96, and the cost of a change in **intended behaviour** would range from £2.24 to £3.86 per person. To evaluate the return on investment for the TTC campaign, we applied a decision model previously described

by McCrone et al.<sup>55</sup> which estimates the impact that reduced stigma and discrimination have on employment among people with depression. The model assumes that some people with depression will not seek help because of stigma and that employment opportunities for people with depression are diminished because of discrimination by potential employers. We explored a number of scenarios for TTC, namely that:

- the campaign results in increased service use of between 1 and 10 percentage points but has no separate impact on employers
- the campaign does not result in increased service use but does increase employment rates for those with reduced depression by 1 to 10 percentage points
- the campaign results in both increased service use and employment rates (again by 1 to 10 percentage points).

Our analysis suggests that the economic benefits of the campaign outweigh the costs, even if the campaign results in only 1% more people with depression accessing services and gaining employment if they experienced a health improvement.<sup>56</sup>

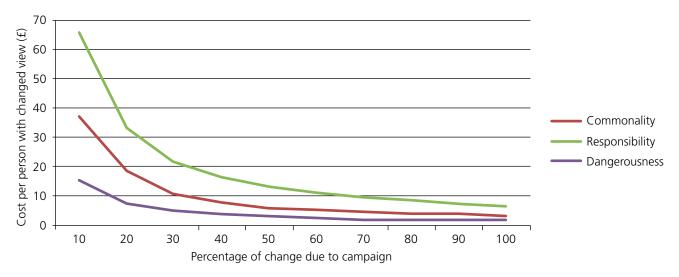
Figure 11.7 Cost per person with changed knowledge associated with the Time to Change anti-stigma social marketing campaign



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Source Evans-Lacko S, Henderson C, Thornicroft G, McCrone P. Economic evaluation of the anti-stigma social marketing campaign in England 2009-2011. British Journal of Psychiatry. Suppl. 2013 Apr;55:s95-s101, http://bjp.rcpsych.org/content/202/s55/s95.full.

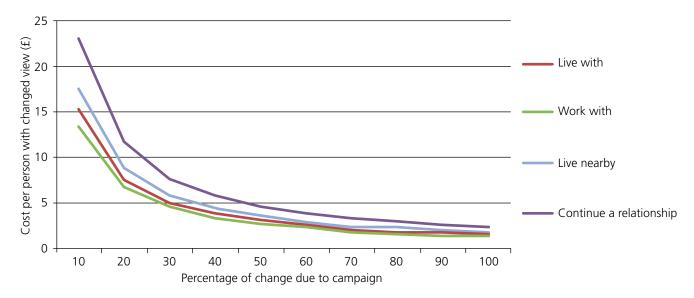
Figure 11.8 Cost per person with changed attitudes (CAMI items) associated with the Time to Change anti-stigma social marketing campaign



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Source Evans-Lacko S, Henderson C, Thornicroft G, McCrone P. Economic evaluation of the anti-stigma social marketing campaign in England 2009-2011. British Journal of Psychiatry. Suppl. 2013 Apr;55:s95-s101, http://bjp.rcpsych.org/content/202/s55/s95.full.

Figure 11.9 Cost per person with changed intended behaviour associated with the Time to Change anti-stigma social marketing campaign.



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Source Evans-Lacko S, Henderson C, Thornicroft G, McCrone P. Economic evaluation of the anti-stigma social marketing campaign in England 2009-2011. British Journal of Psychiatry. Suppl. 2013 Apr;55:s95-s101. http://bjp.rcpsych.org/content/202/s55/s95.full.

## What do we need to know?

- What interventions reduce stigma and discrimination among health professionals?
- How can mental health professionals help people with mental illnesses to cope better with stigma?
- How can the effectiveness of supported employment be increased?
- What workplace interventions help people with mental illness to stay in work/return to work?
- Is appropriate application of the Equality Act 2010 to mental health being made by employers and service providers?
- Do awareness campaigns increase rates of help-seeking for mental illness?
- What is the impact of social media activism on the participants and public when mainstream media report it?
- How will public attitudes and mental health service user experiences of discrimination change after the end of TTC?
- What would be the impact of a reduction in stigma on help-seeking for mental health problems?
- What balance of population-level versus target group-level interventions is needed to achieve the greatest impact on the lives of people with mental health problems?

# Conclusion

The following points are clear from this summary of the relevant evidence. Stigma and discrimination are major barriers to full participation in healthcare, education and citizenship in England. They reduce the opportunities for people with mental illness to gain employment, to receive the quantity and quality of mental and physical healthcare needed, and to form important social relationships. We therefore want to see the operationalisation of the Equality Act 2010 with respect to mental illness in all areas of life, including 'reasonable adjustments' in the workplace, health and social care, education, the justice system, sports and leisure, and political participation.

Since 2007, during the period of the TTC programme, significant but modest gains have been made in the reduction of stigma and discrimination, but most people with mental illness still experience these negative reactions, and many then internalise these forms of rejection in ways that diminish their life opportunities. Hence another key action is to support and evaluate projects that aim to empower mental health service users to respond to stigma and discrimination.

The evidence clearly shows that carefully delivered interventions, both local and national, do reduce stigma and discrimination, if sustained over a sufficiently long term; as the interventions with strongest evidence are those using social contact, our third key action is to develop evidence-based social contact programmes to reduce stigma and discrimination among target groups prioritised by mental health service users.

It is clear that the progress made in stigma reduction in England – which in many ways now leads the world – needs to increase, to progressively reduce what some have called 'the last taboo'.

# **Actions**

We provide a summary of our suggested actions, with details of the bodies and groups that should be responsible for their implementation, in Table 11.1.

#### **Table 11.1 Actions**

	Action	To be carried out by
1	Operationalise the concept of 'reasonable adjustments' per the Equality Act 2010 with respect to mental illness in all areas of life, including the workplace, health and social care, education, the justice system, sports and leisure, and political participation.	Central and local government; clinical commissioning groups; Public Health England; professional bodies
2	Support and evaluate projects that aim to empower mental health service users to respond to stigma and discrimination, e.g. through addressing self-stigma, training in self-advocacy and peer support.	Service user groups; mental health charities; clinical commissioning groups
3	Develop evidence-based social contact programmes to reduce stigma and discrimination among target groups prioritised by mental health service users in surveys such as Viewpoint <sup>1</sup> and Stigma Shout. <sup>57</sup>	Department of Health; the NHS; professional bodies
4	Provide education on the Equality Act 2010, as it applies to providing services to people with mental illness, to professionals working in all public sector organisations.	Central and local government; the NHS; professional bodies
5	Provide information on the Equality Act 2010, as it applies to mental illness, to people with mental health problems.	Clinical commissioning groups
6	Fund access to legal advice for people with mental illness who may have experienced discrimination, including advice in advance of employment tribunal hearings; representation for employment matters heard outside the tribunal system; and representation in appeals to the employment appeal tribunal.	Central government
7	Increase the legal protection offered by the Equality Act 2010 for people with intermittent mental illness.	Central government
8	Add a provision for representative actions (i.e. on behalf of a group of people) to the Equality Act 2010.	Central government
9	Continue long-term funding of TTC and of its evaluation through national surveys of the general public and of mental health service users.	Department of Health
10	Evaluate the implementation of the new Victims' Code as it applies to people with mental health problems, i.e. the provision of enhanced support.	Ministry of Justice; Department of Health
11	Develop evidence-based educational programmes to reduce stigma and discrimination among children and adolescents starting from age 7.	Department for Education; local education authorities; Public Health England; Department of Health
12	Evaluate the new Health and Work Service for employers, employees and GPs with respect to its effectiveness in helping people with mental health problems to retain employment.	Department of Health; Department for Business, Innovation and Skills; clinical commissioning groups

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# Chapter 12

# Mind the gaps – treatment, funding, access and service provision

## **Chapter authors**

Graham Thornicroft<sup>1</sup>, Mary Docherty<sup>2</sup>

- 1 Professor of Community Psychiatry, Institute of Psychiatry, King's College London
- 2 NIHR Academic Clinical Fellow, Institute of Psychiatry, King's College London

# **Key statistics**

- Only a quarter of people with mental illness across Europe receive any form of appropriate treatment, compared with about 80% of people with diabetes.<sup>1</sup> The available data do not enable comparison of these treatment rates in England alone.
- Individuals with psychotic, affective, personality, drugrelated and/or alcohol-related disorders die on average about 15–20 years earlier than people without mental illness.<sup>2-7</sup>
- Since 2011/12 there have been real-terms reductions in investment in mental health in England. Official figures show reductions of 1% for working age adults and 3.1% for older people, from £6.694 billion in total in 2009/10 to £6.629 billion in 2011/12.8 Data from specific NHS trusts indicate far greater real-terms reductions.
- Data are insufficient to enable direct comparison between relative changes in investment in physical health services. In relation to the actual disease burden attributable to mental illness, mental health care accounts for only 13% of NHS spending, whilst mental illness is responsible for 28% of all morbidity in England.<sup>3-8</sup>
- In the period 2005/06 to 2012/13, estimates of the number of adults with mental health problems receiving state-funded social care services showed a 48% reduction in England. This was the largest fall in services provided for any group assessed.<sup>9</sup>

# Key messages

- There is a very significant overall **treatment gap** in mental health, with about 75% of people with mental illness receiving no treatment at all.<sup>1</sup>
- About three-quarters of people with physical disorders receive treatment, while only about a quarter of people with mental disorders do so.<sup>1</sup>
- The treatment gap contributes to unacceptably high mortality rates, as the available data suggest that people with mental illness can die up to 15–20 years earlier on average than people without mental illness.
- Reductions in investment in mental health care, alongside indicators of increasing levels of need, lead to a reduction in available services and compromise patient care and safety.
- **Poor availability of data** makes it difficult to track the treatment provided to people with mental illness (for both mental and physical disorders) using indicators of patient experience and outcomes (including mortality) over time.
- There are still **significant and inappropriate variations** in the delivery of mental health services.<sup>2</sup>
- The current 'outcome frameworks' are poorly coordinated, and fail to provide strong enough incentives to make treatment available to everyone needing mental health care.

# Overview

This chapter presents information to:

- define the concepts of treatment coverage in mental health care provision
- present evidence on the treatment gap for people with mental health conditions in England
- summarise the particular challenges in providing effective coverage
- indicate the most important knowledge gaps related to mental health care in England
- make recommendations for reducing the treatment gap and improving effective coverage for people with mental health conditions.

# Introduction and parameters

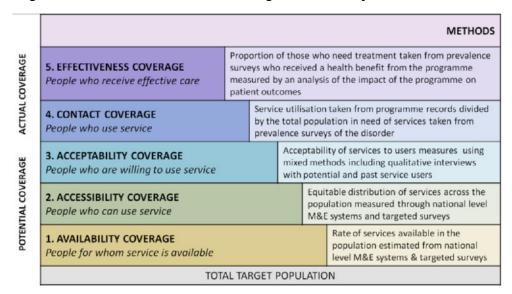
One in four British adults experiences at least one diagnosable mental health problem in any one year, and one in six experiences this at any given time. There is evidence, however, that most people with mental illness in England receive no relevant healthcare.<sup>1,10</sup>

In other words, treatment coverage (namely, the percentage of people who need treatment interventions who actually receive them) is very low. This problem of low rates of treatment coverage has been described by the World Health Organization (WHO) as the mental health 'treatment gap'.<sup>11</sup> Low rates of treatment are not confined to providing mental health care. People with mental illness also receive less and worse treatment for physical illnesses.<sup>12,13</sup> One implication of this is that men with mental disorders on average live 20 years less, and women 15 years less, than the general population.<sup>2-6</sup>

Although the provision of care (also known as 'availability coverage') is necessary, it is even more important that the treatment provided is effective in promoting recovery, and this idea is called 'effective coverage'. In this chapter, 'availability coverage' is used to refer to the quantity of services available to people with mental illness. By comparison, 'effective coverage' is used to refer to 'the extent to which those in need of an intervention get it and benefit from it'.¹⁴ This approach is shown in more detail in Figure 12.1, which also refers to systems for monitoring and evaluating (M&E) these coverage rates.¹⁴

Figure 12.1 gives a schematic representation of levels of coverage in a health system. The proportions of coverage attained vary between sectors and settings.<sup>14</sup>

Figure 12.1 Schema for levels of coverage in a health system



# Particular challenges for providing effective coverage

Effective coverage can be measured by a wide range of outcome indicators in mental health services. It is influenced by:

- the far-reaching consequences of mental illness across different domains, including physical health, employment, housing, social care and the criminal justice system (see Chapter 9 of this report, 'The economic case for better mental health')
- changing mental health needs over the life course, with a need for services and treatments to be responsive during 'at-risk' periods for the development of mental illness (see Chapters 6–8 of this report)
- the existence of stigma and discrimination as major barriers to accessing care (see Chapter 11 of this report, 'Stigma and discrimination')
- the importance of providing culturally sensitive treatment and care options (see Chapter 17 of this report, 'Ethnic inequalities, complexity and social exclusion')
- the need to provide a co-ordinated range of biological, psychological and social interventions that are specific to each person, and are guided by that person's preferences and priorities
- the need for a co-ordinated range of mental health services (including early intervention, crisis resolution, in-patient services, forensic units, psychological therapies, children's services and dementia care)
- the requirement to integrate with a wide range of other agencies (including social care, housing, employment, drug and alcohol and criminal justice system).

## Content and current issues

#### This chapter:

- outlines current knowledge about availability coverage as assessed by data on service provision and treatment rates
- considers the information available on expenditure trends in mental health service provision
- addresses the issue of effective coverage by reviewing the limited available evidence that is relevant, including measures of access, patient centeredness and quality
- reviews data collection systems and considers their limitations in assessing expenditure, treatment rates and effective coverage
- considers the role of commissioning arrangements, activity and outcome monitoring and incentive structures in facilitating effective coverage
- makes recommendations about how to increase effective coverage and how to monitor and evaluate future progress.

# Context

Mental health services in England have historically been characterised by significant variations in service provision, quality of care and acceptability to users.<sup>15</sup> In terms of the policy context, the 1999 National Service Framework for Mental Health (NSFMH) for England aimed to tackle these issues.<sup>16</sup> It set centrally agreed standards and required a particular model of care (including home treatment, assertive outreach and early intervention teams) to be put in place consistently across England. This framework was substantively implemented,<sup>17</sup> largely through strong and financially incentivised performance management methods. Implementation was backed up by increased investment of more than £1.5 billion (around a 50% increase) over 10 years (1999 to 2010),<sup>18</sup> which in particular supported

the creation of specialist community mental health teams across England.<sup>19,18,20</sup> Overall the NSFMH led to notable improvements in the availability and quality of provision in mental health services in England.<sup>21</sup>

Since 2010 mental health services have been subject to a number of policy and economic changes affecting the NHS and society as a whole. The 2011 coalition government's long-term mental health strategy for England<sup>22</sup> set out six key targets, including improvements in safety, patient centeredness, recovery and physical health. It included the commitment to invest £400 million in the 2006 NHS Increasing Access to Psychological Therapies (IAPT) programme over the following four years, to strengthen psychological treatments throughout the NHS and improve access for under-served groups (children and young people, older people and their carers, people with long-term physical health problems and those with severe mental illness). This policy, however, was issued at the same time as the 'Nicholson challenge', which set the NHS (including mental health services) the task of improving quality while making efficiency savings of £15–20 billion between 2011 and 2014. Significant investment changes were made alongside substantial restructuring of commissioning and provider arrangements in the NHS through the 2012 Health and Social Care Act.

Alongside established concerns about the vulnerability of mental health services to these reductions in investment, <sup>23</sup> the Department of Health issued policy guidance in 2014 on attaining equal value – 'parity of esteem' – between mental and physical health services. <sup>2,24</sup> This reflects the historical absence of mechanisms to ensure parity between these services, in terms of both investment and disinvestment, as well as the close association between rates of mental illness and socio-economic deprivation, worsened in times of economic austerity. <sup>25</sup>

More recently, NHS England and Monitor have imposed a 'tariff deflator', which is a fifth higher in 2014/15 for mental health and community organisations than for their acute counterparts<sup>26</sup> (see: www.england.nhs.uk/wp-content/uploads/2013/12/cquin-guid-1415.pdf). This tariff differential does not seem to be aligned with the overall 'parity of esteem' policy direction.

# Service gaps for mental illnessrelated mortality and morbidity

#### **Key messages**

- Mental illnesses are the largest cause of disability in England.
- There is an increasing demand for mental health services, with increases in morbidity across age groups.
- Recession increases both the burden of disease and the disability caused by mental illness.

Mental illnesses have very substantial impacts across England in terms of prevalence, burden of disease and costs. One in six British adults experiences a diagnosable mental health problem at any given time. This makes mental illness the largest cause of disability in England.<sup>27</sup> Mental illness leads to direct costs through health and social care, as well as significant indirect costs through unemployment and the criminal justice system, and hidden costs such as the unpaid care given by family members. The Centre for Mental Health estimates that the aggregated economic and social cost of mental illness in England in 2009/10 was £105.2 billion. This includes £21.3 billion in health and social care costs, £30.3 billion in lost economic output and £53.6 billion in human suffering.<sup>28</sup>

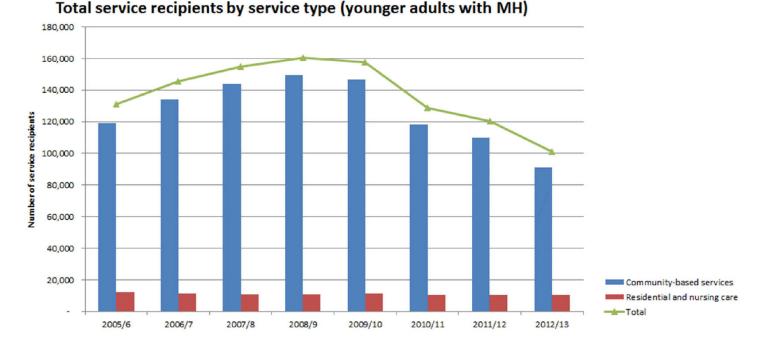
There is some evidence that rates of mental illness are increasing. The 2007 Adult Psychiatric Morbidity Survey, for example, found that the proportion of the English population aged between 16 and 64 meeting the criteria for one common mental disorder increased from 15.5% in 1993 to 17.6% in 2007.<sup>27,29</sup>

Among children, in 2004 the Office for National Statistics estimated that one in 10 children and young people between the ages of five and 16 had a clinically diagnosed mental health disorder.<sup>30</sup> There was no statistically significant change in the rates of disorders over the period following the previous survey in 1999. Nevertheless, increasing numbers of in-patient admissions give an indication of growing pressure on services for children and young people with mental illnesses. There were 3,626 in-patient admissions for child and adolescent psychiatry specialties in 2011/12, compared with 3,136 admissions in the previous year – a 15.6% increase. In 2012/13, total admissions numbered 3,548, with emergency admissions making up 1,574 of that total. The total number of admissions was double that at the turn of the century.<sup>31</sup>

There is an established correlation between household income and the incidence of common mental health disorders, and also evidence that mental health problems increase during times of economic recession.<sup>32–35</sup> The impact of recession on mental health in the UK from 2008 has not been fully established, but there is evidence to suggest that it may be associated with increased incidence of, and disability from, mental illness<sup>36</sup> and increased suicide rates<sup>37</sup> (see also Chapter 15 of this report, 'Suicide and self-harm'). Analysis of unemployment rates before and during the economic recession shows that the gap between unemployment rates for individuals with and without mental health problems widened significantly. Periods of economic hardship may intensify the social exclusion of people with mental health problems, most particularly vulnerable groups such as those with less formal education.25

There is also evidence that a significant number of individuals with mental illness have been disproportionately affected by reductions in expenditure on social care support. A report by the London School of Economics and Political Science (LSE) and the University of Kent revealed that, since 2005, 30,000 people with mental health problems have lost their

Figure 12.2 Total number of adults aged 18–64 with a mental health disorder receiving social care services, by service type



Source Fernandez J-L, Snell T, Wistow G. Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13. Canterbury: Personal Social Services Research Unit, University of Kent; 2013

social care support, following a £260 million shortfall in funding due to cuts in local authority budgets (£260 million in standardised figures and £90 million in observed figures).<sup>9</sup> The standardised estimate for this group showed the largest proportional fall in the volume of service recipients: a reduction of 48%,<sup>9</sup> reflecting the corresponding reduction in investment (see Figure 12.2 and Table 12.1).

Mental health services receive more money per head than any other cause of disability in England. According to 2012/13 programme budgeting data, total primary care trust (PCT) expenditure on mental health services was forecast as £11.28 billion, with problems of circulation (including all cardiovascular diseases) being the next largest spend at £6.9 billion, followed by cancer and tumours at £5.68 billion. Despite this apparently sizeable investment in mental health services, it is striking that, proportionate to the actual disease burden of mental illness, mental health care accounts for only 13% of NHS spending whilst mental illness is responsible for 28% of all morbidity in England.<sup>38</sup>

# The treatment gap

#### **Key messages**

- There is a gross disparity between mental and physical health treatment rates.
- The available data suggest that people with mental health disorders die on average 15–20 years earlier than people without mental illness.

The treatments available for mental illnesses are as effective as the treatments for a range of long-term physical conditions.<sup>39</sup> Yet there is an 'inverse care law' in operation: about three-quarters of people with physical disorders receive treatment, while only about a quarter of people with mental disorders do so.¹ Indeed, proportionately more people with physical disorders are treated in the poorest countries worldwide than are treated for mental disorders in high-income countries such as England (see Table 12.2).

There is evidence that this treatment gap is pervasive across all mental health disorders and all age groups. In England, the most recent National Psychiatric Morbidity Surveys for children and adolescents (2004) and adults (2007)<sup>27,30</sup> show that the large majority of people with all mental disorders except psychosis receive no intervention. For common mental disorders, 24% receive treatment.27 In total, threequarters of all people with anxiety and/or depression receive no treatment at all – approximately 4.5 million adults and 525,000 children.<sup>27,38</sup> Data are not available for the respective treatment rates of individuals in England or the UK with significant long-term physical health conditions (such as diabetes) compared with serious mental disorders. European data provide the closest estimate of this treatment gap, due to similarities in national spending, service provision arrangements and social values.1

There are also particular gaps in the coverage of services for young people, older people and those with physical health problems, as well as physical health services for people with mental health problems.

Table 12.1 Observed and standardised net current expenditure by year (£ millions)
(Adults 18-64 with a mental health problem)

	2005/6	2006/7	2007/8	2008/9	2009/10	2010/11	2011/12	2012/13
observed	1,180	1,180	1,200	1,190	1,210	1,210	1,210	1,210
standardised	1,180	1,160	1,150	1,130	1,140	1,090	960	920

Source Fernandez J-L, Snell T, Wistow G. Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13. Canterbury: Personal Social Services Research Unit, University of Kent; 2013

In relation to conditions often called 'severe mental illness' (this usually refers to people with psychotic disorders),<sup>40</sup> only 65% of people have received treatment in the past year, and 29% have received appropriate physical health checks.<sup>27,41</sup>

20% of adults who screened positive for attention deficit hyperactivity disorder were receiving medication, counselling or therapy for a mental health or emotional problem.<sup>27</sup>

14% of alcohol-dependent adults were receiving treatment for a mental or emotional problem.<sup>27</sup>

14% of adults dependent on cannabis and 36% of those dependent on other drugs were receiving treatment for a mental or emotional problem.<sup>27</sup>

One in six older people with depression discuss their symptoms with their GP, and less than half of these receive adequate treatment.  $^{42}$ 

Despite higher prevalence rates, older people are less likely than working age adults to be diagnosed with depression by their GP, and IAPT services are often not configured to meet their needs, resulting in IAPT access rates of just 5.2%.<sup>27</sup>

Children with behavioural problems that start early (and their parents) rarely receive support. Only 28% of parents of children with a conduct disorder had sought advice from a mental health specialist.<sup>30</sup>

People with long-term health conditions are two to three times more likely to experience mental health problems than the general population, yet the majority of cases of depression among people with physical illnesses go undetected and untreated.<sup>43</sup>

There is evidence of particular problems at points of transition, for example between child and adult services, with many young people 'graduating' from child and adolescent mental health services (CAMHS) but not being accepted for adult services.<sup>44</sup>

In all of these respects, it is clear that very substantial change is required to achieve parity of esteem.

# Funding and investment

#### **Key messages**

- There has been a real-terms fall in investment in mental health expenditure since 2011.
- From the data available, it is difficult to determine how much expenditure nationally and locally goes on services for people with mental illnesses and on which services and how this differs between areas.
- In one case study, an urban mental health trust in England reports that 'in each of our local Clinical Commissioning Groups (CCGs) we have seen net savings from mental health services of at least 32% over the last seven years'.

Table 12.2 The treatment gap: treated prevalence for mental disorders in high, middle and low-income settings1

	High-income countries	Low and middle-income countries	
Physical disorders			
Diabetes	94%	77%	
Heart disease	78%	51%	
Asthma	65%	44%	
Mental disorders			
Depression	29%	8%	
Bipolar disorder	29%	13%	
Panic disorder	33%	9%	

Source original data from the 2002–2004 WHO World Health Survey

#### Mind the gaps – treatment, funding, access and service provision

Table 12.3 Total real-terms investment in adult mental health services, in £'billions, 2001/02 to 2011/12 (at 2011/12 pay and price levels)

Year	Reported investment	Estimated unreported investment	Total investment	Annual increase	% increase
2001/2	4.002	0.160	4.162	_	
2002/3	4.348	0.274	4.622	0.460	11.1
2003/4	4.773	0.040	4.814	0.191	4.1
2004/5	5.309	0.055	5.364	0.550	11.4
2005/6	5.442	0.262	5.703	0.339	6.3
2006/7	5.618	0.194	5.812	0.108	1.9
2007/8	6.066	0.019	6.085	0.274	4.7
2008/9	6.249	0.046	6.295	0.210	3.4
2009/10	6.298	0.338	6.636	0.341	5.4
2010/11	5.780	0.914	6.694	0.058	0.9
2011/12	5.717	0.912	6.629	-0.066	-1.0

The overall real increase in total investment since 2001/02 is £2.467 billion or 59.3% after adjusting for inflation.

Source Mental Health Strategies. 2011/12 National Survey of Investment in Adult Mental Health Services. London: Department of Health; 2012

The availability of mental health services is largely related to investment and expenditure. While real improvements in service quality and quantity were reported during the NSFMH period, <sup>21</sup> there are concerns that overall current expenditure reductions (despite cash injections for psychological therapies) will fail to meet the increasing demand for mental health services and will significantly compromise patient safety and service quality (see: www.theguardian.com/society/2014/mar/12/risks-deep-cuts-mental-health). Nevertheless, the quality of the data available to examine these concerns is inadequate at present. These datasets do not provide sufficient detail to clearly identify local levels of need, nor to identify where particular gaps or variations in investment and service provision exist between areas.

The primary sources of data on national expenditure and trends in mental health investment are the Department of Health's annually commissioned reports on mental health expenditure. Bata are available up to 2012, although the data supplied by PCTs are based on forecasts rather than actual expenditure. This annual reporting process has recently been decommissioned, meaning no national-level data are available beyond the 2011/12 report. NHS England is expected to publish data on mental health spending in 2012/13 in 2014, and the NHS Confederation continues to provide its annual factsheet, which details trends in expenditure, service usage and burden of disease, integrated from a number of sources.<sup>29</sup>

The other primary source detailing NHS expenditure in each clinical and geographical area is programme budgeting data. Each CCG reports on its annual expenditure in mental health as part of the programme budgeting process, as one of 23 categories. The level of detail in these reports is rather limited: for example, mental disorders are categorised as 'substance misuse, organic mental disorders, psychotic disorders, child and adolescent, or other'. For 2006/07, all but one PCT reported more than 90% of their expenditure as being within the 'other' category.

The available data, shown in Tables 12.3 and 12.4, indicate a real-terms decrease in mental health service expenditure in England in recent years, especially for specialised community mental health teams. The 2011/12 survey found that investment in mental health services for adults of working age (aged 18–64) dropped by 1% in real-terms from the previous year. This was the first real-terms drop in investment since the survey began in 2001/02.29 In cash terms, there was an increase of 1.2% in 2011/12, to a total of £6.629 billion. The BBC and the online journal Community Care, however, published figures in December 2013 from 43 out of 51 mental health trusts, based on responses to freedom of information requests. Comparing 2011/12 budgets with those for 2013/14, they found a real-terms reduction of 2.36% over the two-year period. Conversely, funding for psychological therapies increased by 6% in real terms compared with 2010/11.

Table 12.4 Real-terms investment in priority service areas, 2002/03 to 2011/12

Year	Assertive Outreach	Crisis Resolution/ Home Treatment	Early intervention in psychosis	Total in £ million	Real increase %	Actual increase £
2002/3	77.5	38.2	8.0	123.6	_	_
2003/4	95.5	73.2	15.7	184.4	49	60.8
2004/5	112.9	130.3	28.1	271.3	47	86.9
2005/6	118.0	180.5	48.7	347.2	28	75.9
2006/7	122.2	206.5	57.4	386.1	11	38.9
2007/8	137.5	235.2	76.1	448.8	16	62.8
2008/9	140.8	254.8	99.5	495.2	10	46.3
2009/10	141.1	259.9	107.3	518.4	5	23.2
2010/11	138.6	266.1	104.1	520.0	0	1.6
2011/12	126.8	254.6	109.3	490.7	-6	-29.3

Real term increase 2002/3 to 2011/12 in £'millions is 367.1

Source Mental Health Strategies. 2011/12 National Survey of Investment in Adult Mental Health Services. London: Department of Health; 2012

Between 2010/11 and 2011/12, investment across the three priority areas (crisis resolution, early intervention and assertive outreach) fell (for the first time) by £29.3 million, from £520 million to £490.7 million. This is significant given the evidence base for these services reducing admissions and the co-existing reduction in bed availability.<sup>17</sup> Funding for older people's mental health services was also found to be under greater pressure, with a 1% fall in cash terms from the previous year to £2.83 billion in 2011/12. This represents a decrease in real terms of 3.1%. Some data suggest that service reductions may have been greater in London than in other areas of England.<sup>45</sup>

There are no comparable data for CAHMS (Child and Adolescent Mental Health Services). Young Minds' most recent survey found that 67% of councils had reduced CAMHS funding between 2010 and 2013. Regional cuts in spending were as high as 12% in the North East and 13% in the East of England.<sup>46</sup>

Despite such figures suggesting real-terms decreases in expenditure of between 1 and 2%, case study information from individual trusts indicates that these figures fall significantly short of the real impact of such cuts. The case study below illustrates the experience of one urban mental health trust in England.

# Box 12.1 The experience of an urban mental health trust in England

#### Overview

This case study is based on analysis from one large urban mental health trust of the overall movements in NHS funding from four Clinical Commissioning Groups for financial years from 2009/10 to 2013/14. Information was collected for all boroughs relevant to the trust. Contract values total £250m from these four commissioners. Changes were assessed in all aspects of NHS funding. Changes in contracts can be described under four headings:

#### Inflation

There has been an increase in the contract value for inflation – predominantly pay awards but also other inflationary pressures such as supplies, the Clinical Negligence Scheme for Trusts, drugs and specific initiatives. The commissioners are funded for this from the Department of Health and pass it on to providers. Until recently commissioners have been receiving substantial real-terms growth in addition to the inflation. For the period in consideration the inflation funding has been £36 million.

#### Efficiency/cost improvement plans

Every year since 2009/10 there has been a requirement for internally generated efficiency gains – although these are notionally paying for more clinical activity for the same funding, or in reality for the same clinical activity for less funding because of the block contract model that applies to mental health services. This means that there have been real cost reductions and these changes are increasingly difficult to make without impacting on service delivery (although of course this can be a positive change and lead to improvements in quality). These changes are called cost improvement plans (CIPs). CIP requirements have been: 3.0% in 2009/10, a further 3.5% in 2010/11, 4.0% in 2011/12 and 4.0% each year since – we anticipate that this will continue at this level for the next five years.

Prior to 2010/11 inflation funding exceeded the efficiency requirement, resulting in a net flow of funds into the trust. In 2010/11 they were the same amount for each local contract and since 2011/12 the CIP has exceeded inflation, meaning in effect a reduction in the value of the contract. To put it another way, the trust funds its own inflation pressures out of efficiencies and gives funding back to the CCGs. Over the period, generic efficiencies have totalled £42 million. These funds are then available to the commissioner for investment.

In 2014/15 this is a net reduction for mental health of 1.8% going back to CCGs (2.2% inflation offset by 4% efficiency) and has been the subject of fierce debate because of the differential between the acute and non-acute contracts.

# Disinvestment/Quality, Innovation, Productivity and Prevention Programme

Over the same period we have seen disinvestment within the CCGs in relation to the Quality, Innovation, Productivity and Prevention Programme, and although it should be about system change and improvement (releasing funds for quality and investment in services), it has become synonymous with the 'Nicholson challenge' of the funding gap of £20 billion (now re-estimated at £30 billion) between expected demands and available funding in the NHS over the next five years. The overall disinvestment over the period has been £24 million in the local contracts.

#### Specific investments

There has been specific funding and investment for initiatives such as IAPT (some of this funding comes specifically from the Department of Health), some specialist services, quality initiatives – this totals only about £18 million over the period.

#### **Summary**

In summary, therefore, the trust over this period has seen a net reduction in funding of £12 million, and in recent years the pace of net disinvestment has been accelerated and is set to do so further. If the funding provided by the Department of Health passes through CCGs (or where service transfers that have no overall effect are excluded from this – £38 million in total) then the net gain to local CCGs from disinvestment and efficiency in local mental health services has been approximately £50 million. In each of the local CCGs net savings from mental health services of at least 32% over the last seven years are seen.

In relation to the investment of resources in mental health services in England, drawing together all the relevant data sources it seems fair to conclude that:

- information on mental health service expenditure currently lacks sufficient detail
- there is a clear fall in investment and expenditure, despite evidence of an increase in the mental health burden<sup>8,28,46</sup>
- it is unclear whether the disinvestment has been greater for mental than for physical health provision
- there appear to be considerable discrepancies between overall national figures for resource reductions and the figures available locally from some mental health trusts
- there are no available datasets that capture the implications for mental health services of aggregate expenditure reductions across multiple sectors (the criminal justice, social care, non-statutory and voluntary sectors)
- there is some evidence of deteriorating quality of care, for example in terms of increasing numbers of young people treated in adult in-patient wards, or increasing numbers of people detained under the Mental Health Act<sup>29</sup>
- it is unclear whether disinvestment in services has been driven by evidence-based quality improvement decisions to generate efficiency savings while preserving quality.

# Providing effective coverage

The quality of healthcare can be assessed in relation to: accessibility, effectiveness, responsiveness (or patient centeredness) and safety.<sup>14</sup>

#### **Accessibility**

#### Crisis response

The risk of individuals presenting in crisis is increased in the absence of appropriate preventative and early intervention care. In NHS crisis care services, four out of 10 mental health trusts have staffing levels below established benchmarks, as evidenced by the following sources:

- www.mind.org.uk/news-campaigns/campaigns/crisis-care/ about-the-campaign/?ctald=/news-campaigns/campaigns/ crisis-care/crisis-care-slices/we-need-excellent-crisis-care/
- www.mind.org.uk/media/553149/mind-briefing-onmental-health-provision.pdf
- www.mind.org.uk/media/498970/ commissioningexcellence\_web-version-2.pdf

MIND has shown that only one-third of people in crisis are assessed within four hours (see: www.mind.org.ug/crisiscare). The average length of time people wait in police cells for assessments under section 136 of the Mental Health Act is nine hours and 36 minutes, with some people waiting up to 20 hours.<sup>47</sup>

#### Box 12.2 Domains of effective coverage

Accessibility requires the assessment of: (i) the physical availability of services; (ii) the geographical accessibility of services (i.e. services being located where people can use them); (iii) the acceptability of services, in that people want to use them and are satisfied with their quality; (iv) the appropriate delivery and effectiveness of services, so that people are able to receive the expected health benefits from them; (v) equity, in that services are equally accessible to those who could benefit from them, irrespective of their age, gender, socio-economic status or ethnic group.

**Effectiveness** is the extent to which intended improvements in health are actually attained, measured by the change in patient clinical outcomes as a result of being treated.

**Safety** means how far potential adverse outcomes are prevented or avoided as a result of the interventions provided. Serious adverse events include, for example, deleterious side-effects from psychotropic medication, increased risk of suicide and premature mortality from other causes.

**Responsiveness** (or patient centeredness) is the extent to which patients' needs are placed at the centre of a system, measured by service user reports of their experience of services, the timeliness of services and the continuity or co-ordination of care across providers and time.

## Mind the gaps – treatment, funding, access and service provision

There is an increasing use of the police and criminal justice system to 'care' for individuals who are unwell due to insufficient capacity in mental health services to respond to this demand. In 2011/12, more than 9,000 people were detained in police custody under section 136, while 16,035 were taken to hospital.<sup>47</sup> Data show an increase in emergency calls requiring the presence of the police, indicating an overall increase in crisis presentations alongside rising admission rates.<sup>48</sup>

Concerns have been expressed by clinical staff and patients about the real, felt impact of the current increase in demand for in-patient services, alongside reductions in beds. Relevant sources include:

- www.bbc.co.uk/news/uk-27285555
- www.bbc.co.uk/news/health-24537304
- www.bbc.co.uk/news/uk-england-norfolk-27207055

Readily available data sources to illustrate this trend have been difficult to access, resulting in freedom of information requests to investigate these concerns. NHS England provides data on national bed occupancy across all health sectors, but detail is not available on the percentage occupancy of mental health beds (see: http://www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-and-occupancy/bed-data-overnight).

The Care Quality Commission (CQC) has raised concerns about bed occupancy rates for many years.<sup>49</sup> The most recent CQC report does not give bed occupancy rates: www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-and-occupancy/bed-data-overnight/.

In 2013, freedom of information requests submitted by the BBC and the online journal *Community Care* and returned by 46 of England's 58 mental health trusts showed that a minimum of 1,711 mental health beds had been closed since April 2011, including 277 between April and August 2013. This is a 9% reduction in the total number of mental health beds – 18,924 – available in 2011/12. Three-quarters of the bed closures were in acute adult wards, older people's wards and psychiatric intensive care units<sup>50</sup>: http://www.communitycare.co.uk/2013/10/16/patients-at-risk-as-unsafemental-health-services-reach-crisis-point-2/#.U3WoVq1dUv0.

CAMHS report being particularly badly affected. A 2013 survey of members of the Faculty of Child and Adolescent Psychiatry asked about their experience of admitting young people to in-patient units. 77% of respondents from England reported difficulties in accessing admissions to in-patient beds; 79.1% of respondents reported safeguarding concerns/incidents while waiting for a bed; 76.5% reported young people with unacceptably high risk profiles being managed in the community due to lack of beds; and 61.9% reported young people being held in inappropriate settings.<sup>51</sup>

The consequences of bed shortages include higher thresholds for admission and increased reliance on the use of out-of-area private sector beds. The BBC and the online journal *Community Care*, using freedom of information data from

30 trusts, reported that the number of patients sent out of area has more than doubled between 2011/12 and 2013/14 (from 1,301 in 2011/12 to 3,024 in 2012/13). The costs associated with this, reported by 23 trusts, show an increase in expenditure from £21.1 million in 2011/12 to £38.3 million in 2012/13 (see: http://www.bbc.co.uk/news/uk-27285555). Increased private sector bed usage is costly, requires strict governance systems to ensure appropriate transfer of clinical information, and is frequently highly distressing for patients, family/carers and staff if transfers are required during periods of crisis away from familiar clinical teams and friends and family.

#### Equity and ethnicity

There are higher prevalence rates of suicide, in-patient admissions and admissions under the Mental Health Act (1984) in black and minority ethnic (BME) groups (see Chapter 17 of this report, 'Ethnic inequalities, complexity and social exclusion'), indicating that these people do not often have their needs effectively identified and met. Evidence also suggests that there is greater mistrust of mental health services by people in BME groups.<sup>52</sup> Recently, intervention studies tailored to the specific needs of BME groups with mental illness have shown a range of benefits over more traditional mental health care.<sup>53,54</sup>

#### Waiting times for treatment

Mental health services currently have an exemption from the 18-week maximum waiting time for service access stipulated in the NHS Constitution. For psychological therapy, for example, a MIND service user survey showed that over 12% of people wait longer than a year to start treatment, while 54% wait longer than three months. 55 National figures for waiting times for treatment are not clear, despite this being a key performance indicator of the IAPT programme (see: www.iapt.nhs.uk/data/current-performance/).

The development of IAPT has been a significant step forward in providing a structured and systematic approach to improving timely access to appropriate treatments. <sup>56,57</sup> Yet there are also equity issues to address for the IAPT programme. The further development of IAPT for people with severe mental illness will be important in assessing its ability to meet need in this area, as will its availability to older adults, as at present only 6% of over-65s access IAPT, despite the 12% expected access rate<sup>55</sup> (see: www.iapt.nhs.uk/equalities/older-people).

Despite the progress of IAPT, a recent survey of people using talking therapies found that 58% were not offered a choice in the type of therapies they received, three-quarters were not given a choice of where they received their treatment, and 11% said that they had to pay for treatment because the therapy they wanted was not available on the NHS. People who are offered a full choice of different types of psychological therapy are five times more likely to report that therapy helped them to return to work.<sup>58</sup>

#### **Effectiveness**

The information available on the effectiveness of interventions for people with mental illnesses is at present incomplete and is not well co-ordinated. The challenges that need to be addressed include the following:

- It is often necessary to take a multi-dimensional approach: for example, to assess the symptom, disability and quality of life changes produced by treatment.
- NHS provider organisations do not routinely collect clinically relevant repeated outcome measures for most people treated.
- The social and vocational care sectors have not yet developed a culture that focuses on outcomes.
- The outcome frameworks that apply to primary and secondary healthcare providers are not linked in a way that allows appraisal of the effectiveness of the whole system providing care to people with mental illness.
- Locally returned data used for national statistics largely consist (with the exception of suicide rates) of process measures (such as number of admissions) rather than outcome measures (such as recovery or mortality rates).
- Measures intended to reduce unwarranted variations in clinical practice, such as National Institute for Health and Care Excellence guidelines, are not given a strong emphasis at national or local levels to support their implementation.

Furthermore, several structural issues limit the collection and use of outcome measures across the wider health economy:

- Health and wellbeing board strategies rely on joint strategic needs assessment (JSNA) data to set local priorities, but there is no requirement for JSNAs to cover the full range of local needs, including mental healthrelated needs.
- CCG commissioning plans may not be fully aligned with the Health and Wellbeing Strategy.
- The low rates of treatment, especially for particular minority ethnic groups, mean that any assessment of need based upon those in contact with services will not generate information about the people who are not treated.
- The progress made in some sectors such as IAPT, where key process and outcome variables are collected routinely, has not been generalised to other areas of mental health care.

#### Safety

Mental illness is a strong risk factor for completed suicide.<sup>59</sup> The latest reports from the National Confidential Inquiry (NCI) into Suicide and Homicide by People with Mental Illness find that suicide rates for mental health patients in England have risen, with 1,333 deaths in 2011. The NCI speculates that the rise 'probably reflects the rise in suicide in the general population, which has been attributed to current economic difficulties'.<sup>60,61</sup> Discussion of the higher rates of chronic physical disorders among people with mental illness and

their implications are discussed in detail in Chapter 13 of this report, 'Physical health and mental illness'.

#### Responsiveness

Early intervention and preventative services are designed to respond early to signs of illness and prevent deterioration that results in admission. Although these services were a previous priority investment, funding for them has begun to decline in some parts of England, while the number of hospital admissions has continued to increase and is now about double the figure for 2000.<sup>29</sup> While notionally working on the principle of offering the 'least restrictive care', use of the Mental Health Act has grown steadily in recent years. In 2012/13 there was a 4% increase in compulsory detentions in comparison with the previous year.<sup>62</sup>

Service user experience has recently been assessed in a national survey, which found that more than half of people who had received psychiatric in-patient care did not think that the settings and facilities had helped their recovery.<sup>63,64</sup>

In 2013 the CQC, in its survey of community mental health services, <sup>65</sup> found that:

- more information and involvement in decisions was needed concerning medication, care planning and care reviews
- of those prescribed new medications, 28% said they had not been told of possible side-effects and 16% felt they were not provided with easily understood information about the medicine
- 46% of those on the Care Programme Approach 'definitely' understood the contents of their care plan – 2% fewer than in 2012
- 32% reported that they had not had support with employment
- 27% of care plans showed no evidence that the person whose plan it was had been involved in its creation.

In parallel, the CQC report on use of the Mental Health Act<sup>66</sup> showed that:

- inappropriate restrictive practices and culture in many wards demonstrated a 'significant gap between practice and the ambitions of the Department of Health's mental health policy 'No Health without Mental Health'
- services appeared to be under severe pressure for many reasons, including under-provision of approved mental health professionals, limited transport to hospital, high bed occupancy rates, increased workloads and insufficient access to psychological therapies.

# Synthesis of key findings

- Mental health services are not currently achieving appropriate availability coverage, as evidenced by the treatment gap.
- There is evidence that the services that do exist are being strained further, reducing effective coverage.
- A significant problem in evaluating effective coverage is the lack of systematic, appropriate and mandated use of activity and outcome measures to enable evaluation of the effectiveness of services at both local and national levels.
- Significant variation in practice, activity and outcome is suspected, but no datasets exist to allow appropriate comparison of spending and outcomes between trusts.
- Systems are not currently embedded to collect meaningful quality and effectiveness data (meaningful to people with mental illness as well as to clinical staff).
- At present, services are not planned with clear systems to evaluate appropriate measures of activity and outcome, thereby facilitating evaluation of the effectiveness of services.

Mental health services in England have been described as the 'best in Europe'.<sup>67</sup> This claim sits very uneasily with the facts set out in this chapter, which show that most people with mental illness in the country go untreated, and face mental and physical outcomes far below what they and their family members expect.<sup>65</sup> Such a claim in fact shows how poor mental health services are across Europe compared with their physical health equivalents.<sup>68</sup> This degree of systematic disregard or neglect of the needs of people with mental illness has been described, in policy terms, as a form of structural discrimination <sup>69,70</sup>

The recent governmental commitment to 'parity of esteem'2 is therefore both long overdue and sorely needed. Policy requirements that aim to improve acute healthcare, such as the 18-week waiting list limit, are still not applied equally to mental health care. It is also clear that unintended consequences of the tariff system, at each stage of its implementation, have systematically disadvantaged mental health commissioner and provider organisations. Poorly integrated monitoring processes have contributed to a failure to alert all parts of the health economy to how far resource reductions have harmed the quantity and quality of mental health care in England in recent years. In the post-2013 structure of the NHS in England, separate health, social care and public health outcomes frameworks are making it harder to commission joint or integrated services —and to avoid gaps in provision where the desired outcomes of those services are not shared.

# Author's suggestions for policy

- Increase the involvement of people with experience of mental health problems at every stage of commissioning and care provision, to inform a strong understanding of where the gaps in effective service provision are and how they can be closed.
- Set specific metrics to assess critical aspects of mental health service performance, including rates of effective coverage and mortality rates for people with mental illness.
- Co-ordinate and incentivise routine data collection of key indicators of mental health service activity, patient experience and patient outcomes. An Atlas of Variation would provide a fundamental first step in establishing where key gaps in services exist (and the nature and degree of variation) to inform commissioning processes.
- There should be no further disinvestment in mental health services.
- Ensure parity of funding for mental health services compared with the acute sector, and provide real incentives for investment, alongside robust monitoring to assess detailed trends in service quantity and quality over time.
- Ensure that all health professionals (in both primary and secondary care and across specialties) are adequately trained, resourced and incentivised to identify and treat people with mental health problems, including the prevention and treatment of co-morbid physical disorders.
- Establish transparency indicators in national and local priority setting and funding, to monitor allocations related to treatment and care for people with mental illnesses.
- Waiting times for mental health services should be included in the NHS Constitution, with parity with those for acute care.
- The health, social care and public health outcomes frameworks should include better integrated care as a shared goal, and people using health and social care services should be asked to rate their experiences of 'seamless care', which should feed into financial incentive systems.
- Increase service user input and research into alternative service models to deliver care to hard to reach and vulnerable groups, for example through examining the effectiveness of innovative service models and third sector organisations to support people and groups within society who are otherwise unwilling to engage with statutory services and tend to fall through gaps in provision.

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# Chapter 13

# Physical health and mental illness

# **Chapter authors**

Matthew Hotopf<sup>1,2</sup>, Lance McCracken<sup>3</sup>

- 1 Professor of General Hospital Psychiatry, King's College London, Institute of Psychiatry
- 2 Director NIHR Mental Health Biomedical Research Centre, South London and Maudsley NHS Foundation Trust
- 3 Professor of Behavioural Medicine, King's College London, Institute of Psychiatry

# **Key statistics**

- People with a chronic medical condition have a 2.6-fold increase in the odds of having a mental illness, compared to those without a chronic medical condition.<sup>5</sup>
- Between 12% and 18% of spending on long-term conditions is related to "poor mental health and wellbeing", translating to between £8 and £13 billion in NHS expenditure in England.<sup>19</sup>
- Estimates suggest that about 60% of the excess mortality in people with mental illness is avoidable.<sup>4</sup>
- International evidence shows that people with schizophrenia are about half as likely to receive coronary revascularisation procedures as those patients without a severe mental illness.<sup>54</sup>

## Overview

There is a complex, dynamic relationship between mental and physical health. People with mental illness experience poor physical health with higher than expected mortality, which is not explained by suicide.<sup>1-3</sup> Much of this excess mortality is potentially avoidable. People with chronic physical diseases have a higher prevalence of depression and other mental disorders, and co-morbidity is associated with a range of poor outcomes and increased costs.5 Enhancing management in mental health may improve outcomes in physical health and vice versa.<sup>6,7</sup> However, there are many structural barriers which inhibit the provision of care that optimises both mental and physical health. This chapter will briefly review the extensive literature on the ways that physical and mental health interact, the mechanisms involved and potential solutions, before making suggestions for changes in health systems that might lead to better integration and patient outcomes. In this chapter the predominant focus is on the relationships between physical disease and mental illness. It does not address mental illness associated with childbirth; medically unexplained symptoms; the impacts of drug and alcohol consumption on physical health or cognitive impairment in general medical settings - however, many of our suggestions also apply to these areas.

# Mental health in people with long-term conditions

Physical diseases such as cancer, heart disease, stroke and diabetes create a burden of symptoms, reduce our sense of security, and can restrict our ability to meet responsibilities and reach our goals in life. They create discomfort, and this can limit what we are able to do. They can also create financial strains due to missed work or added expenses, and may cause family strains. Even when they do not do any of these things, they can leave us with a fear that our future may include discomfort, restrictions or strains.<sup>8–10</sup> Such diseases burden the sufferer with the need to seek

treatment, take medications and follow complex routines of health monitoring, when they would rather be doing other things. The journey a patient with a long-term condition (LTC) takes is often one of loss, threat and uncertainty, which are established risk factors for anxiety and depression.

Given the impact of many LTCs on patients' lives, it should come as no surprise that 'common mental disorders' (CMDs), including depression and anxiety, are highly prevalent among people with LTCs. A World Health Organization population survey of 245,000 individuals in 60 countries showed that between 9% and 23% of participants with one or more chronic physical conditions met the criteria for depression, with higher rates in those with multiple morbidities.<sup>11</sup> Similar rates for 'anxiety disorders' have been shown for people with physical conditions.<sup>12</sup> A systematic review of the 12-month prevalence of major depression in people with chronic medical illness, including congestive heart failure (CHF), hypertension, diabetes, coronary artery disease, stroke, chronic obstructive pulmonary disease (COPD) and end stage renal disease (ESRD) showed prevalence rates ranging from 7.9% for CHF to 17.0% for ESRD, or 8.8% for any condition. As a whole, this represented a 2.6-fold increase in the odds of having a mental illness if one also has any chronic medical condition.<sup>5</sup> A study in nine western European countries (including the UK) has shown that, particularly in older adults, associations between physical health and depression are consistent across countries.13

When clinical samples are studied, the prevalence of depression and anxiety is even higher than described in population surveys. For example, nearly 50% of women with breast cancer recruited from a London hospital had depression, anxiety or both in the year after diagnosis. 10 In a study of myocardial infarction based in Manchester, 20% of those affected had depression, with a further 21% of those followed over a year developing depression in that time.<sup>14</sup> Similar high rates of depression and anxiety are found in other samples in England, such as 28% with depression or anxiety or both in a clinical sample with diabetes in Birmingham; 15 24% of patients with diabetes and foot ulcers in London;16 and 56% with depression in a sample admitted to hospital with COPD in Manchester.<sup>17</sup> When populations of patients attending clinics are screened for depression, probable major depression is most common in pain clinic patients (61%), but is also highly prevalent for conditions such as rheumatoid arthritis (23%), complex orthopaedic injuries (22%) and hepatitis C (19%).18 While these estimates vary according to disease, setting and measurement of CMD, the key message is that CMDs are highly prevalent with LTCs.

Depression and anxiety may be characterised as understandable responses to the experience of LTCs. However, it is a common mistake to equate understandability with inevitability and untreatability. Interventions at individual and population level may well reduce the impact of LTCs and directly treat mental illness (see below).

Long-term conditions: Mental illness: 30% of population of 20% of population of **England** (approximately England (approximately 15.4 million people) 10.2 million people) 30% of people with a 46% of people with a long-term condition have a mental illness have a longmental illness (approximately term condition (approximately 4.6 million people) 4.6 million people)

Figure 13.1 Overlap between long-term conditions and mental illness<sup>19</sup>

Source adapted from Naylor C., Parsonage M., McDaid D., Knapp M., Fossey M., Galea A., 2012. Long-term conditions and mental health: the cost of co-morbidities. London. The King's Fund.

# The impact of mental illness in the context of LTCs

Mental illness causes a direct burden of suffering and has major impacts on quality of life and functioning. In a large population study based in East Anglia, the functional impairment independently associated with anxiety or depression was of equal magnitude to that associated with the presence of diabetes, cancer, myocardial infarction or stroke.<sup>20</sup> In potentially disabling conditions, experiences of fear and anxiety associated with symptoms can impose greater restrictions on daily functioning than do the symptoms themselves.21 It has been shown that in population-based studies of older people, symptoms of depression increase the risk of becoming physically disabled and decrease the chance of recovery from disability, independent of chronic health conditions.<sup>22</sup> International reviews of the evidence show that, among people with a range of physical conditions, those who also have co-existing depression and anxiety have higher functional disability, greater loss of productivity, and greater health resource use.5, <sup>23, 24</sup> It has also been shown that psychological distress is a predictor of mortality from

- (a) heart disease in people who are initially free of heart disease<sup>25</sup> and
- (b) any cause, including those from cardiovascular disease and cancer.<sup>26</sup>

In addition to the direct additive effects of multiple comorbid physical and mental illness, there may be specific processes through which physical and mental illnesses interact and amplify adverse impacts. People with coronary heart disease and depression have greater difficulty in taking their medication appropriately<sup>27</sup> and in making other health-promoting behaviour and lifestyle changes, such as adhering to a low fat diet, taking regular exercise, reducing stress and increasing social support.<sup>28</sup> Possibly through these or related processes, people who have had a myocardial infarction and who also report significant symptoms of depression have higher rehospitalisation rates, more frequent chest pain, greater physical limitations, lower quality of life and higher mortality rates than those who do not report significant symptoms of depression.<sup>29</sup>

In diabetes, the total adverse effects of CMD also appear greater than the sum of their parts. A survey of people with diabetes indicated that higher severity of depressive symptoms was associated with poorer diet and medication adherence, greater functional impairment and higher healthcare costs.<sup>30</sup> Another survey of people with diabetes showed that those with both depression and diabetes experienced significantly lower quality of life on every measured domain of quality of life, including both physical and mental components.<sup>31</sup> Prospective studies demonstrate that poorer physical and mental health-related quality of life is associated with higher total mortality.<sup>16,32</sup>

These adverse outcomes and increased service use are costly. The King's Fund and Centre for Mental Health reviewed the costs of LTCs<sup>19</sup>, identifying data mainly from North America. The evidence, however, is consistent – the presence of a mental illness always increases non-mental health care costs, and in many instances these are doubled. The report concluded that between 12% and 18% of spending on LTCs is related to "poor mental health and wellbeing", translating to between £8 and £13 billion in NHS expenditure in England.

# Physical health in people with mental illness

The evidence that mental illnesses such as schizophrenia and bipolar illness, addictions and depression are associated with a reduction in life expectancy is incontrovertible. Recent evidence from the South London and Maudsley NHS Foundation Trust, using the Clinical Record Interactive Search system,33 indicates that life expectancy is between 10 and 17 years lower than expected.<sup>2,3</sup> This means that severe mental illnesses have a greater impact in reducing years of life than many cancers, diabetes or smoking, and that people with severe mental illness(es) have life expectancies closer to those seen in low or middle-income countries than those seen in the UK. The illnesses associated with the greatest loss of life years are substance use disorders and severe mental illnesses such as schizophrenia and schizoaffective disorder; however, loss of life years is also seen in people with depression and other CMDs.<sup>2</sup> The excess mortality in people with mental illness is seen in other developed countries too,<sup>34</sup> and may indeed be worse where universal healthcare is not available.<sup>35</sup> The pattern is not limited to those who receive treatments for mental illness – community surveys indicate that depression detected through questionnaires or interviews in non-help-seeking individuals is associated with a 1.5 to two-fold increase in mortality. 36-38

The reasons for these reductions in life expectancy are complex and cannot be explained by an excess of single risk factors or causes of death. While suicide rates are undoubtedly raised in people with mental illness(es),<sup>39</sup> contributing to between one-fifth and one-third of all deaths,<sup>40</sup> the relative risk of mortality is still considerably raised when deaths by suicide are omitted. Further, there is considerable evidence that the incidence and prevalence of many major physical diseases is higher in individuals with mental illness.<sup>41–43</sup>

Many potential causes for the excess mortality in people with mental illness exist (see Box 13.1). The most obvious candidate causes of this health disparity are health behaviours, and above all, smoking. There is strong evidence that the prevalence of smoking is higher in people with mental disorders, <sup>44</sup> with one UK sample finding that 60% of those receiving secondary mental health care smoke. <sup>45</sup> Addiction to tobacco among smokers with severe mental illness is also stronger than in smokers in the general population. <sup>46</sup> Further, the gap between people with mental

illness and the general population in terms of smoking prevalence is increasing over time (Szatkowski and McNeill, under review).<sup>47</sup> Evidence indicates that many patients want help to stop<sup>48</sup> but often do not receive it, perhaps because of stigmatised attitudes by health professionals.<sup>49</sup>

Aside from smoking, there is no shortage of evidence that people with mental illness lead less healthy lives, with higher rates of obesity, lower exercise levels, poor diet and high alcohol and drug consumption. There are particular concerns regarding the impact of medication (particularly medicines used in the treatment of schizophrenia and related disorders) on weight gain, leading to obesity and type 2 diabetes. Despite compelling evidence that health behaviours such as smoking, drug and alcohol consumption, poor diet and sedentary lifestyles are more prevalent in people with mental illness, it is not established that these alone drive the excess mortality. Many case registers do not have sufficient information to determine the role of such risk factors in driving mortality, and cohort studies typically find that an effect remains after controlling for such factors.

Beyond health behaviours, other risks may emerge in the way that patients use services and that way that services respond to patients. For example, people with mental illness may be less likely to take up preventive interventions such as vaccinations or cancer screening,<sup>51</sup> or may present late with a physical disease. There is also evidence that the presence of a mental illness may confound the usual process of diagnosis and treatment – so called 'diagnostic overshadowing'52 – which may not be an overtly discriminatory process but a reflection of the difficulty faced by a doctor when diagnosing in the face of complexity. However, there is also no shortage of evidence that, for one reason or another, patients with mental illness have reduced access to many treatments and procedures.53 International evidence shows that people with schizophrenia are about half as likely to receive coronary revascularisation procedures as those patients without a severe mental illness.54 There is evidence that patients with mental illness have considerably poorer survival rates from cancers diagnosed at the same stage than the general population – the reasons for this are unclear.<sup>55</sup> Major mental disorders have been cited as an overt exclusion criterion from certain treatments such as transplantation and bariatric surgery, although it is unclear how widespread and explicit this practice is in the UK.56,57 Finally, mental illness may impair decision-making capacity, leading to difficult ethical decisions for doctors about the provision of long-term lifesaving treatments (e.g. renal dialysis) in people who may not understand their benefits or trust the care system. 58,59

Estimates suggest that about 60% of the excess mortality in people with mental illness is avoidable,<sup>4</sup> but it is unclear how best to improve life expectancy in this group. The diverse range of drivers of excess mortality and morbidity in people with mental illness means that strategies for health improvement should ideally be multi-pronged. The next section discusses some of the measures that might be taken to address these issues.

# Box 13.1 Candidate causes of excess mortality in people with mental illness

- Health behaviours e.g. smoking, diet, exercise, alcohol and drugs<sup>60</sup>
- Altered help seeking e.g. delayed presentation, reduced treatment adherence, poor uptake of health screening, impaired mental capacity leading to treatment refusal
- 'Diagnostic overshadowing' e.g. failure by health professionals to recognise physical health problems in people with mental disorders.
- Discriminatory policies
- latrogenic factors e.g. obesity caused by antipsychotic medication.<sup>50</sup>
- Social conditions e.g. homelessness, unemployment, poverty
- Suicide and violent victimisation
- Direct physical impacts of mental disorders e.g. changes to immune function

# Improving the mental health of patients people with LTCs

#### **Prevention**

There has been limited research on the prevention of mental illness in patients with LTCs. However, patients value responsive services where healthcare professionals are effective and sympathetic communicators. <sup>61</sup> There is evidence that communication skills training for healthcare professionals reduces distress in their patients. <sup>62</sup> A number of psychological and educational treatments aimed at improving understanding of illness, motivating patients to adhere more effectively to treatments and enhancing coping strategies have direct beneficial effects on quality of life, reduction in symptoms and impacts on physiological parameters. <sup>63–65</sup> Such approaches, particularly when applied early during the development of LTCs, appear relevant across the population of patients with these conditions, rather than solely for those with demonstrable mental illness.

#### **Treatment of mental illness in LTCs**

There is substantial evidence from randomised trials that the conventional treatments for depression and anxiety work irrespective of the presence of co-morbid physical disease. Recent systematic reviews conclude that psychosocial interventions, typically including forms of cognitive behavioural therapy, are able to improve health-related quality of life and anxiety for people with coronary heart disease, <sup>63</sup> depression for people with diabetes <sup>65,66,67</sup> and cancer, <sup>7</sup> and disability and depression in patients with chronic pain. <sup>68</sup> Certainly high-intensity treatments, such as those

including combinations of physical exercise and psychosocial methods, are shown to improve anxiety, depression and quality of life in people with COPD<sup>69</sup> and to produce similar results for people with chronic pain.70,71 In other reviews it has been concluded that exercise training can have a small beneficial effect on anxiety and depression symptoms<sup>72,73</sup> in people with chronic illnesses. Mindfulness-based treatments reduce depression, anxiety and psychological distress in people with physical illness in general.74 Included in this latter review were treatments for people with chronic pain, cancer, rheumatoid arthritis, chronic fatigue and heart disease. Similarly, there is substantial evidence that antidepressants are effective in depression associated with physical illness,75 although current guidance restricts their use to those with a history of more severe depression, in whom the depression is complicating other treatments or is highly persistent.<sup>76</sup>

#### Screening

Screening to detect depression in patients with LTCs has been recommended by the National Institute for Health and Care Excellence (NICE),<sup>76</sup> although there is evidence that it is ineffective as a stand-alone intervention.<sup>77</sup> If screening is to work, it has to be done in tandem with the development of care pathways that offer a different approach to management once depression is detected. This is illustrated by the TEAMcare approach, where a population approach to identification and management of depression in patients with heart disease or diabetes not only improved depression outcomes, but also improved diabetic control, blood pressure and cholesterol levels.<sup>6</sup> The key components of the intervention included:

- (a) screening to identify patients with depression;
- (b) case management delivered by general nurses with some mental health training;
- (c) use of simple techniques such as problem-solving, coaching and education;
- (d) optimisation of medication, including antidepressants;
- (e) supervision of case managers within a multidisciplinary team, including physicians and psychiatrists; and
- (f) proactive ongoing review of outcomes.

The trial demonstrated the cost-effectiveness of the intervention, which is now being implemented in the USA under the TEAMcare programme. A similar approach has been successfully used in the UK to identify and manage depression in cancer.<sup>7</sup>

For screening to work, it needs to be possible to conduct it on large numbers of patients in routine care. The Integrating Mental and Physical Healthcare – Research Training and Services (IMPARTS) programme developed in King's Health Partners has demonstrated that routine screening in secondary care is feasible. Patients attending general hospital clinics are asked to complete questionnaires recording physical and mental health outcomes on an e-tablet. Results are uploaded in real time to their health record, which can then prompt clinicians with information

about relevant care options, as well as providing patients with information salient to their LTC. Such platforms have the capacity to transform care by making routine the collection of information on the subjective experiences of patients, in the same way that blood pressure or weight are monitored.

# Box 13.2 Case study '3 Dimensions for Diabetes (3DFD)'

The 3 Dimensions for Diabetes (3DFD) project developed at King's College Hospital is an exemplar of joint working between mental health, social care and physical health settings. Patients with diabetes who have difficulties with glycaemic control are offered a bio-psycho-social assessment, leading to interventions that might include support with housing or debt, treatments for mental disorders, and help optimising diabetic control. The pilot has established that this approach can lead to improved glycaemic control, reduced hospitalisations and significant cost savings. Such a service is a promising model for integrating care in LTCs.<sup>78</sup>

## Improving physical health in people with mental illness

Relatively few trials have been conducted that attempt to address the physical health of people with severe mental illness. Consensus statements have made recommendations about the need for physical healthcare monitoring in severe mental illness,<sup>79</sup> and the Lester Adaptation – a programme of screening and intervention endorsed by the Royal College of Psychiatrists and the Royal College of General Practitioners – provides a framework for assessment and intervention. Such interventions have been tested – a small randomised controlled trial in the United States Veterans Association indicated that integration of primary care within mental health systems was effective at improving uptake of screening and other public health interventions.80 However, as this trial was based in the USA it is difficult to generalise to a UK setting. A systematic review indicated that nonpharmacological trials aimed at weight reduction were effective in those with severe mental illness.81 However, the single most important target at the individual level is smoking because it is highly prevalent, its harms to health are well understood (as are the benefits of stopping) and behaviour change interventions are effective. The guestion therefore is not whether to act on this target, but how best to implement what is already known. NICE recently suggested a number of interventions, including mandatory recording of smoking status by mental health trusts; education for mental health workers on smoking cessation; smoke-free policies on NHS trust grounds; rapid referral to enhanced smoking cessation services; and encouragement and support to stop for those mental health workers who smoke.82

# Bringing the agenda together: difficulties, policy and suggestions

Current government policy documents, such as *No Health Without Mental Health*<sup>83</sup> and *Closing the Gap*<sup>84</sup> acknowledge many of the issues raised in this chapter. Similarly, the British Medical Association (BMA) has recently published a farreaching report on the topic, <sup>85</sup> and the Royal Colleges of Psychiatry, General Practitioners and Physicians identify similar issues in their report *Whole Person Care: From Rhetoric to Reality.*<sup>86</sup> The King's Fund and Centre for Mental Health have also made far-reaching recommendations based on economic analyses.<sup>19</sup> There is, then, a growing consensus that something should be done. The next section attempts to identify where we think the NHS could most effectively address the issues raised.

# Service configuration and commissioning

If mental illnesses are a common consequence of physical disease and are associated with poor outcomes, commissioning structures should recognise this and ensure that mental health needs are met. However, mental health services are typically physically and culturally displaced from acute care providers. As the population of individuals with multi-morbidity grows, so the need for integration of care, with primary care at its heart, grows. However, the complexities of the secondary care system do not encourage integration of care for people with multi-morbidities. This fracturing of services is mirrored and perpetuated by separate commissioning structures – with mental and physical healthcare commissioning typically taking place in different silos, using different mechanisms of reimbursement (tariffs for acute care and block contracts for mental health) and providing limited opportunity for joint working. The authors of this chapter suggest that commissioners are provided with the requisite training and expertise to anticipate mental health needs when commissioning acute services. We understand that NHS England has allocated funds to train commissioners to assess mental health needs when commissioning care, and we support this innovation. The authors further suggest that a mechanism is established by which commissioning decisions in one sector have to take account of the likely needs of patients from the other sector's perspective – thus mental health commissioning should take account of the physical health needs of patients, and vice versa. The response to such assessments will vary according to local circumstances, but might include embedding psychologists, Improving Access to Psychological Therapies (IAPT) services or liaison psychiatrists in acute care clinics, and the greater use of general practitioners or physicians working within psychiatric in-patient units or community services.

Liaison psychiatry services are multidisciplinary mental health teams residing within general hospitals, which provide crisis care in emergency departments and address the mental health needs of patients with complex patterns of comorbidity. Liaison services are usually provided by mental health trusts and commissioned within a block contract for mental health. There is growing evidence that such services may be cost-effective by reducing the length of acute hospital stays and providing integrated care for patients with multimorbidity.87 However, their development has been hampered by commissioning arrangements, because the part of the health system that feels their benefits (acute care) is usually not responsible for their commissioning. Historically there has been little incentive for mental health commissioners to push for more liaison psychiatry services. Meanwhile, because acute commissioners may see mental health as somewhat remote, it is easy to ignore the mental health needs of the populations served. So, while a newly commissioned acute service might anticipate the need for provision of support services such as physiotherapy or radiology, there is often a failure to anticipate mental health needs until after the service is established and the complexity of the patients' difficulties becomes apparent. We therefore suggest that liaison psychiatry services are commissioned across acute care, and that such services are not confined to emergency departments but provide in-reach to acute hospital in-patient and out-patient services. While models for liaison psychiatry services in primary care are less well established, the need for better integration of care suggests that further liaison psychiatry services should be commissioned to operate across the primary/secondary care interface.

Liaison psychiatry services are typically reactive and generic, providing care across general hospitals. For specific LTCs there is scope for more population-based and proactive services, for example services provided by clinical or health psychologists or IAPT services embedded in clinics. Such services would ideally span the primary/secondary care divide, as the majority of patients with LTCs and co-morbid mental disorders reside in the community and are cared for by general practitioners. There are well developed models of fully integrated care in the UK, such as interdisciplinary pain management treatments (see the recent evidence-based review and guidance provided by the British Pain Society: http://www.britishpainsociety.org/book pmp2013 main.pdf). A number of additional integrated care pilots are under way in England, 88,89 and provide opportunities to reduce barriers between mental and physical health services. Such work has the potential to bridge primary and secondary care, with the aim of serving the public health needs of populations more explicitly than typically happens now. We suggest that research is commissioned to provide evidence on the effectiveness and cost-effectiveness of alternative models of care, including physical health input for community and in-patient mental health services; primary care clinical and health psychology; and liaison psychiatry services and collaborative care models. There is also a lack of research evidence on optimising physical health in patients with CMDs.

# Outcomes and clinical informatics

There are many barriers and enablers to integration. It is typically impossible to gain information on care provided in another sector. One potential solution to this is the development of health records which are accessible to patients and contain key information from each provider. For example, the South London and Maudsley NHS Foundation Trust has developed a platform – 'myhealthlocker' – which enables such sharing of records across sectors. We suggest that research be commissioned to test the effectiveness of providing such shared platforms on processes of care and clinical outcomes.

Many of the issues covered in this chapter are of direct relevance to the NHS Outcomes Framework; the inclusion of premature mortality in adults aged under 75 with severe mental illness is an important innovation. We suggest that such a reporting system is backed up by regular national audits – akin to the National Confidential Inquiry into Suicide and Homicide – which might go beyond the bald figures and assess the drivers of premature mortality, providing rapid feedback to services. These audits might be provided by expanding upon the Royal College of Psychiatrists' National Audit of Schizophrenia.

Elsewhere many of the outcomes relating to quality of life for people with LTCs, perceived quality of services and responses to people with acute injuries clearly relate to the need for better integration of mental and physical healthcare. Attaining improved outcomes requires the joined-up commissioning referred to above, as well as innovations in informatics to ensure that mental health outcomes relevant to LTCs are captured routinely.

### Sharing the agenda

There is a risk in complex systems of care that lines of accountability and expectations are confused and leadership is unclear. One example is the question of who should provide physical health screening, monitoring and management in mental health care. According to the Quality Outcomes Framework, the emphasis is placed on GPs. The 2014 NICE guideline on schizophrenia gives welcome emphasis to physical health, 90 but expects health monitoring to be primarily the role of the GP. Arguably, the promotion of good physical health (including long-term disease management) should be core business for providers across sectors, and mental health services should be given incentives to do more to enhance the physical health of their patients in collaboration with colleagues in primary care. Rethink's Integrated Physical Health Pathway, 91 developed in collaboration with relevant professional bodies, is a good example of how physical health may be promoted by joint working between the mental health and primary care sectors. The main targets for such intervention should probably be

smoking cessation and management of the cardiometabolic risk factors of obesity, diabetes and hypertension. Effective tobacco control policies for people with mental disorders are needed, including rapid access to smoking cessation services. <sup>92,93</sup> Mental health professionals should be confident in giving advice about smoking cessation, as well as ensuring that patients are referred to smoking cessation services. We suggest that quality indicators are developed to ensure that mental health services routinely attend to the physical health needs of patients.

The culture of mental health services has often appeared to use risk of self-harm, suicide and violence as drivers to determine who receives care. There is limited evidence that risk assessments are able to predict those at greatest risk with sufficient positive predictive values to enable a preventive strategy to be put in place, mainly because the events to be averted are rare and risk factors are insufficiently predictive. 94,95 However, if the same approach of risk assessment and management was taken by mental health services to known physical health risks, such as smoking, the benefits to the health of the public are likely to be much more direct. Further, patients with severe mental illness who are at high risk of self-neglect appear to have the highest excess mortality.96 Such patients are often those with psychotic disorders and prominent 'negative' symptoms. Their perceived low risk of self-harm or violence may lead services to discharge them, while ignoring their potential to enhance self-care and avert premature mortality.

#### Workforce issues

If services are to be better integrated, the needs of the populations served will not be met simply with a proliferation of specialist services that cross sectors, but by providing those looking after patients with multi-morbidities with the skills required to take account of their mental and physical health needs at the same time. The government's *Closing the Gap* recommendations<sup>84</sup> suggest the need for training programmes to improve awareness of mental health issues among NHS staff. A recent BMA report<sup>85</sup> places emphasis on better integration of mental health training throughout the medical curriculum, and such attempts to place psychiatry at the heart of medicine are welcome. The report similarly recommends that all foundation year doctors have psychiatry placements, a recommendation with which we agree.

However, the workforce issues may be even more significant in nursing. Nurses are the largest staff group in the NHS, often have much more intense patient contact than doctors, and may be best placed to act in a case management or integrative role. Yet nurse training is split from the outset into mental and general nursing, with limited opportunities to gain skills from the other side. We suggest that there is a need to examine the possibility of greater integration of physical and mental health in nurse training. Similar arguments probably exist for other professions allied to medicine.

### Box 13.3 The benefit of collaborative care

On 28th August 2014 three studies by researchers from Oxford and Edinburgh universities were published in The Lancet, The Lancet Oncology, and The Lancet Psychiatry (see below). These studies describe the estimated prevalence of depression in cancer patients, the treatment gap and the efficacy of an integrated treatment programme for major depression in people with cancer. The studies were funded by Cancer Research UK and the Scottish government. This work provides more evidence that integration of care for people with multi-morbidities will be of substantial benefit to patients.

To access the articles named below please visit http://www.thelancet.com/themed/depression-and-cancer

Prevalence, associations and adequacy of treatment of major depression in 21 151 cancer outpatients: a cross-sectional analysis of routinely collected clinical data.

Integrated collaborative care for comorbid major depression in cancer patients (SMaRT Oncology-2): a multicentre randomised controlled effectiveness trial.

Integrated collaborative care for major depression comorbid with a poor prognosis cancer (SMaRT Oncology-3): a multicentre randomised controlled efficacy trial in patients with lung cancer.

#### Conclusion

Ultimately, the words 'physical' and 'mental' seem like they describe very different matters, and this in itself may create problems. If from there we formally separate diagnostic schemes, the training of professionals, and systems for delivery of services into these two realms, these apparent differences are probably accentuated further. In fact the differences between the processes underlying these aspects of total health are probably created more by our use of the separate words than by the nature of the processes themselves. It may be more useful some of the time to see health as an integrated totality, one that includes our physiological functioning, our behaviour and all of the influences on the two. In the meantime, if we can begin to see the separation of the two not as a matter of actual, distinct, underlying differences, but as a tool for understanding the whole, that may be a positive step.

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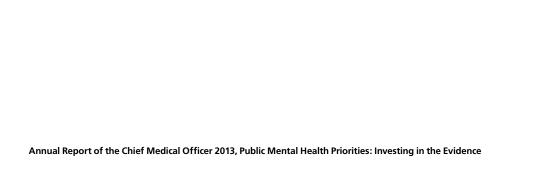
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Section 6 Needs and safety



# Chapter 14

# Violence and mental health

#### **Chapter authors**

Louise M Howard<sup>1,2</sup>, Jennifer Shaw<sup>3,4</sup>, Sian Oram<sup>5</sup>, Hind Khalifeh<sup>6,7</sup>, Sandra Flynn<sup>8</sup>

- 1 Professor in Women's Mental Health and NIHR Research Professor, Institute of Psychiatry, King's College London
- 2 Consultant Perinatal Psychiatrist, South London and Maudsley NHS Foundation Trust
- 3 Professor of Forensic Psychiatry and Consultant Forensic Psychiatrist, University of Manchester
- 4 Consultant Forensic Psychiatrist, Lancashire Care NHS Foundation Trust
- 5 Lecturer, Institute of Psychiatry, King's College London
- 6 Academic Psychiatrist, King's College London
- 7 Consultant Psychiatrist, South London and Maudsley NHS Foundation Trust
- 8 Research Fellow, Centre for Mental Health and Risk, University of Manchester

### Key statistics

- In the 2009/10 British Crime Survey (now known as the Crime Survey for England and Wales), a nationally representative household survey, 21% of people with self-reported chronic mental illness reported past-year actual or threatened violence, compared with 9.9% of those without such a condition.¹
- People with severe mental illness are between three and 10 times more likely to have been victims of past-year violence than the general population.<sup>2,3</sup> Women with mental illness are at particularly high risk of domestic and sexual violence.<sup>2,3</sup>
- More than a quarter of the burden of adult psychiatric disorders is attributable to the effect of experiencing childhood violence or abuse.<sup>4-6</sup>
- In total, 14% of English newspaper articles from 2011 (in 27 local and national newspapers studied) featured stigmatising language that referred to people with mental illness as a danger to others.<sup>7</sup>
- A Swedish study found that 64% of violent crime is committed by 1% of the population; of this 1%, 3.9% have been admitted to a psychiatric hospital for a mental illness.8
- A total of 5% of serious violent crime in England and Wales is perpetrated by patients under the care of specialist mental health services.<sup>9</sup>
- People with severe mental illness are twice as likely to be violent if they have a history of non-adherence to medication combined with substance abuse problems.<sup>10</sup> Mental illness alone is not a reliable predictor of violence: contextual and situational factors are equally important in estimating risk.<sup>11</sup>

#### Overview

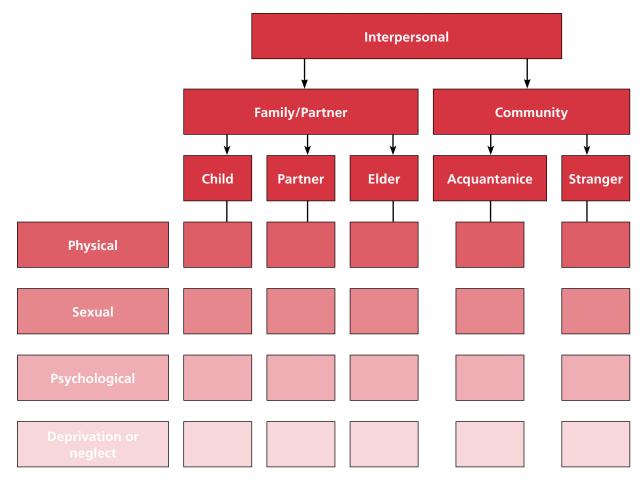
Violence is a pervasive problem in our society. It includes physical, sexual and psychological abuse, coercive behaviour and deprivation. Violence can be perpetrated by family members, intimate partners and ex-partners (domestic violence), or by strangers and acquaintances (non-domestic or community violence, including violence by care providers)<sup>12</sup> (see Figure 14.1).

By extrapolation from the findings of the Crime Survey for England and Wales, there are an estimated 2.5 million violent incidents in England and Wales each year. These result in 300,000 visits to Accident & Emergency departments and 35,000 emergency admissions to hospital, while the physical and mental consequences of violence cost the NHS approximately £2.9 billion every year. 13 A total of 3% of participants in the Crime Survey for England and Wales report past-year community violence (where most victims are men) and 6% report past-year domestic violence (where most victims, particularly of repeated or severe domestic violence, are women).14 Sexual violence is reported by 0.3% and 3% of men and women respectively. Therefore, by extrapolation, in 2012 around 1.2 million women suffered domestic abuse, over 400,000 women were sexually assaulted, 70,000 women were raped and thousands more were stalked. 15 A review of population-based studies in high-income countries reported that 5-35% of children are physically abused, 5-30% of children are sexually abused and 10-20% of children witness domestic violence.<sup>16</sup> An NSPCC survey in the UK had similar findings, with one in five children reporting serious physical abuse, sexual abuse or severe physical or emotional neglect at some point in their lifetime.<sup>17</sup>

The ecological model for understanding violence (see Figure 14.2) provides a theoretical framework to help explain the multi-faceted nature of violence, which occurs not only as a result of individual characteristics that increase the likelihood of being a victim or a perpetrator of violence (e.g. age, education, history of abuse, income, substance misuse), but is also related to the nature and proximity of social relationships, community characteristics such as high population density, unemployment and social isolation, and larger societal factors including health, educational, economic and social policies, cultural norms, gender disadvantage and social inequalities.

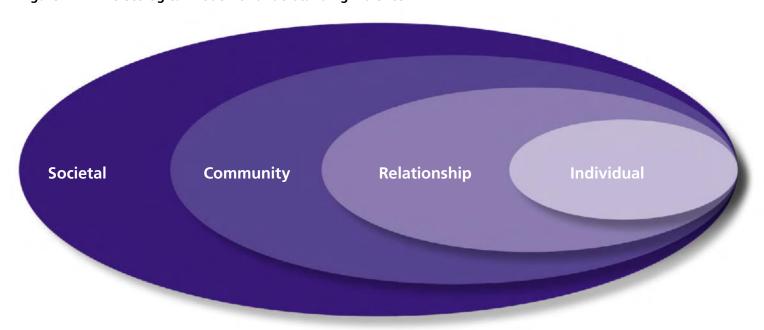
Being a victim of violence in childhood or adulthood is associated with the development of mental disorders. 4-6,18-21 In addition, people with a pre-existing mental disorder are more vulnerable to being a victim of violence. 22 A growing body of evidence has found that people with pre-existing mental illness are up to 10 times more likely to be victims of violence than the general population. 2,3,23-25 The risk of being a perpetrator of violence in people with mental disorders (mainly severe mental disorders) is approximately two to three times higher than in the general population, 26,27 with psychiatric patients in England and Wales committing 5% of serious violence9 and 10% of homicides. 28

Figure 14.1 World Health Organization typology of violence<sup>12</sup>



Source Adapted from Krug E, Mercy J, Dahlberg L, Ziwi A. The World Report on Violence and Health. Lancet 2002

Figure 14.2 The ecological model for understanding violence



NB: This figure does not imply proportionality; the extent of each of these levels is not known due to the limited evidence available Source Adapted from Dahlberg LL, Krug EG Violence-a global public health problem

# Mental illness and experiences of being a victim of violence

## Violence as a risk factor for subsequent mental illness

Violence experienced in childhood or adulthood is associated with the subsequent development of mental illnesses. Childhood physical and sexual abuse is associated with adult onset common mental disorders and psychosis, 5,6,29 and it has been estimated that between a quarter and a third of the burden of adult psychiatric disorders is attributable to the effect of childhood abuse.<sup>6</sup> In addition, being a victim of sexual or domestic violence in adulthood is associated with the onset and persistence of depression, anxiety, eating disorders, substance misuse disorders, psychotic disorders and suicide attempts. 4,5,18,19,21 Sexual and physical violence are also commonly experienced by refugees and victims of trafficking.30 Studies suggest that both childhood sexual abuse and violence experienced during trafficking are associated with an increased risk of mental disorder<sup>31</sup> and psychological distress.30,32

Risk factors for being a victim of violence include witnessing domestic violence as a child, childhood abuse, being bullied, and parental substance misuse.<sup>5,33</sup> Violence and abuse against children could be reduced by preventing child sexual exploitation, providing parenting interventions for highrisk families, preventing bullying at schools, safeguarding vulnerable children and adults, helping troubled families, community youth violence prevention and reducing the availability and harmful use of alcohol. These are all public health measures<sup>13</sup> that could potentially address the key goals of the Government's mental health strategy<sup>34</sup> to improve mental health and ensure fewer people suffer avoidable harm.

- Violence against adults with pre-existing mental illness
- In the 2009/10 British Crime Survey, 21% of people with chronic mental illness reported past-year violence, compared with 9.9% of those without such a condition.¹ Chronic mental illness was defined as a long-standing mental health condition or disability that had lasted or was expected to last 12 months or more and that limited day-to-day activities.
- In terms of population burden (using Crime Survey data), there were an estimated 137,000 annual incidents of violence against people with chronic mental illness, at an estimated cost of £1.3 billion.¹
- Crime Survey data also show that men with all forms of mental illness are at particular risk of community violence, but are also at increased risk of being a victim of domestic violence compared with men without mental illness.<sup>20</sup>
- A systematic review and meta-analysis of observational studies in high-income settings estimated that around one in four people with mental illness has been a victim of any

- type of violence in the past year, a threefold risk compared with the general population.<sup>2</sup>
- Systematic reviews and meta-analyses have found that women with depression and anxiety disorders have a two to threefold increase in the risk of domestic violence,<sup>21</sup> with over 10% of postnatal depression potentially attributable to domestic violence.<sup>35</sup>
- Other research suggests that people with pre-existing severe mental illnesses are between twice and 10 times as likely to be victims of violence as the general population.<sup>2,3,24,25,36</sup> In a Victim Support and MRC-funded survey, 38% of women with severe mental illness reported being the victim of rape.<sup>3</sup> A systematic review found that domestic violence rates among female psychiatric patients ranged between 20% and 50% (inter-quartile range data).<sup>37</sup>

Violence is associated with significant mortality and morbidity, including injuries, chronic physical illness, poor reproductive and sexual health, adverse perinatal outcomes, substance misuse, mental illness and suicidal behaviour. 12,38 Adverse health outcomes are magnified for people with pre-existing mental illness, with evidence suggesting that victims with mental illness are more likely to self-harm and become socially isolated following victimisation than victims without pre-existing mental illness.<sup>1,3</sup> Being a victim of violence is associated with a worse prognosis for the underlying psychiatric disorder, increased hospitalisation, co-morbid post-traumatic stress disorder and a poorer quality of life compared with psychiatric patients who have not been victims of violence.<sup>39–42</sup> Although data on fatal violence are limited, a Swedish national study found that people with any psychiatric disorder had a fivefold risk of being murdered compared with those without a mental disorder.<sup>43</sup>

# Box 14.1 Why researchers use self-reported violence data

A key advantage of the use of crime surveys in the general population is that they measure self-reported experiences of violent and non-violent crime, whether or not these experiences were reported to the police or other criminal justice agencies. The alternative is officially recorded crime statistics (i.e. crime statistics based on police or court records), which are subject to variations in the rates of reporting of crimes by victims to criminal justice agencies, differences across time and place in the recording and classification of crimes by these agencies, and political pressure to demonstrate the effectiveness of crime prevention policies.<sup>93</sup> Therefore crime surveys are seen as a more reliable measure of crime experiences.<sup>94</sup>

There are additional considerations when researching violence in people with severe mental illness. Officially recorded crime may underestimate victimisation among psychiatric patients even more than among the general population: MIND reports that psychiatric patients are less likely to report victimisation to criminal justice agencies than victims in the general population. 60 Although self-reported measures may be subject to specific biases – such as those arising from cognitive impairment (which may affect the ability to recall crime over a specific time period) or those arising from symptoms such as suspiciousness or persecutory ideas (which may lead to over-reporting of crime) – several studies have demonstrated the reliability of self-reported victimisation by psychiatric patients, including those with severe psychotic disorders. 23,95,96

# Risk factors for experiencing violence in people with mental illness

In the general population, key risk factors for being a victim of community violence are being aged 18-25, being male, being socially deprived, misusing substances and perpetrating violence.<sup>44</sup> Risk factors for sexual and domestic violence include being female and aged under 25, being socially deprived and having a history of childhood abuse.<sup>45</sup> The higher prevalence of many of these factors among people with psychiatric disorders may explain some of their excess victimisation risk.<sup>24</sup> Some risk factors are unique to people with severe mental illness, including acute psychotic illness, where manic disinhibition may lead to exploitation or persecutory delusions may lead to social conflict and violence. 46,47 Research by Victim Support found that people with mental illness attributed their victimisation experiences to negative attitudes towards their personal attributes, including their mental illness as well as their race, sexual orientation and/or physical disability.3 Key modifiable risk factors of relevance to clinical practice include substance misuse and poor service engagement, 3,48 while key factors of relevance to public health include social exclusion, stigma, homelessness and unemployment.

#### **Detection and interventions**

Most violence prevention research in the NHS has focused on domestic violence, which is recognised to be a major public health and clinical problem requiring a healthcare response (including recently published NICE guidance). 49 Domestic violence is under-detected in both primary and secondary care, 50,51 only 10-30% is detected in secondary mental health care.51 Community violence is similarly poorly detected in secondary mental health care.3 Most mental health care professionals and GPs have little or no relevant training in experiences of violence, may find it difficult to facilitate disclosure by patients experiencing abuse and are uncertain about further management after disclosure.<sup>52</sup> Barriers to disclosure for people with mental illness include the fear of consequences, including not being believed, and the risk of further violence if the perpetrator discovers that there has been a disclosure.53

Recommendations by an NHS Taskforce on Violence Against Women and Children<sup>54</sup> and recently published NICE guidance on the prevention and reduction of domestic violence<sup>49</sup> therefore include training clinicians to ask about experiences of violence in a sensitive, non-judgemental way, with signposting to appropriate local referral and care pathways that ensure safety and promote recovery (e.g. safety planning, help from sexual assault referral centres, multi-agency risk assessment conferences for people at high risk of severe domestic/sexual violence or homicide, referral to advocacy, treatment with trauma-focused psychological interventions). A cluster randomised controlled trial of an intervention that included training of GP practices and the integration of third sector domestic violence advocate educators into primary care demonstrated significant improvements in the identification and referral of victims of domestic violence.<sup>55</sup> This intervention is now being implemented, thereby improving GP care of victims of domestic violence (see case study) and has similarly been piloted in a secondary mental health care setting, with reductions in abuse and improvements in quality of life reported.<sup>56</sup> For people whose safety has been addressed but who have continuing symptoms, effective interventions include trauma-focused psychological treatments.57

However, there is evidence that third sector organisations do not always provide support for people with mental illness: for example, refuges may not accept women with a history of schizophrenia or substance misuse.<sup>58</sup> Commissioners therefore need to ensure that services for people who have experienced violence and abuse are available for all victims, including those with severe mental disorders and substance misuse problems.<sup>59</sup>

# Box 14.2 Case study – specialist domestic violence advocacy in primary care for women with indicators of domestic violence, including depression or anxiety

Women accessing specialist domestic violence advocacy have a reduced recurrence of physical abuse and an improved quality of life. <sup>97</sup> A cluster randomised controlled trial (the IRIS trial) <sup>55</sup> tested a training and support primary care programme that included practice-based training sessions for clinicians and administrative teams, a prompt within the medical record to ask about abuse, and a referral pathway to a named domestic violence advocate (who delivered the training and further consultancy). One year after the second training session, advocacy agencies recorded a threefold increase in the rate of disclosures of domestic violence, and a sixfold increase in self- and direct referrals of patients to advocacy from intervention practices compared with control practices.

After publication of the trial findings and an analysis showing that the intervention was cost-effective, a programme was developed that could be commissioned by clinical commissioning groups or local authorities. To date, 13 localities in England have commissioned IRIS, and it will be implemented in South Wales in 2014. More than 700 women are being referred annually to IRIS domestic violence advocates by their GPs in the areas that have implemented the programme. This is estimated to be at least six times the number of referrals occurring in the absence of IRIS. This means that a safer and more appropriate response by clinicians to disclosures of domestic violence can be implemented in primary care.

#### Interface with the criminal justice system

There is evidence from interviews carried out by third sector organisations that people with mental illness experience discrimination within the criminal justice system. 60 Key barriers to accessing justice include not being believed, being seen as unreliable witnesses and having their mental illness used against them in court.3,60 A recent study by researchers at the University of Bristol found that rape victims with mental illness were the least likely to progress through the criminal justice system.<sup>61</sup> CPS (Crown Prosecution Service) guidance to prosecutors states that the credibility and reliability of witnesses with mental illness should be guestioned only under the same circumstances as for other witnesses (e.g. in relation to inconsistencies and evasion) and not solely on the basis of their mental illness.<sup>62</sup> In addition, the police and courts are required to make reasonable adjustments<sup>63</sup> (including special measures such as giving evidence from behind a screen or via video link, and assistance from Registered Intermediaries) to support vulnerable witnesses (including people with mental illness) to give evidence.64

However, interviews by third sector organisations with patients and practitioners indicate that these measures are often ignored in practice.<sup>3,60</sup> MIND recommends that inappropriate or insensitive disclosure of mental health problems by the defence should be challenged.<sup>65</sup> A criminal incident in which a person has been targeted because of their disability, including disability due to mental illness, is considered to be a more serious crime than a similar incident without a 'hate crime' element;<sup>66</sup> evidence of this should be brought to the attention of the CPS and the court.<sup>67</sup>

# Violence perpetrated by adults with mental illness

There is evidence of a risk of violence by people with serious mental illness, particularly schizophrenia and psychosis. Compared with the general population, men with schizophrenia are four to five times more likely to be violent, while for women the risk is increased eightfold.<sup>27,68–70</sup> The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCISH) has shown that the proportion of violence committed in England and Wales by patients in contact with mental health services 12 months before the offence is 5% for serious violence9 and 10% for homicide.<sup>28,9</sup> In a study from the US, violence committed by people with mental illness was examined by diagnostic group. The risk of violence was found to be highest among individuals with alcohol or drug disorders at 25% and 35% respectively, more than twice the level among people with schizophrenia (13%). Similar rates of violence have been recorded in people diagnosed with major depression and common mental disorders (11–13%),71 but most violence research has been carried out on people with severe disorders.

Most people with mental illness are not violent, and most people who are violent are not mentally ill. The estimated attributable risk of violence by people with mental illness has been shown to range from 3% to 5%.72 However, there is a widely held belief that people with mental illness are violent and unpredictable. Evidence for this was recently provided by Thornicroft et al. (2013), who reported that, of English local and British national newspaper articles reporting mental health topics in 2011, 14% referred to the mentally ill as being a danger to others.<sup>73</sup> Data from NCISH show that in England on average each year 57 patients in recent contact with specialist mental health services commit a homicide; of these, eight kill a stranger. 28 Although intimate partners and former intimate partners constitute 19% of the victims of homicide committed by psychiatric patients,<sup>28</sup> little is known about the association between mental illness and the perpetration of domestic violence.<sup>26,74</sup>

# Risk factors for people with mental illness being a perpetrator of violence

There are a number of established risk factors for violence, which fall into four categories: dispositional, clinical, historical and contextual. Dispositional factors refer to personality and behavioural features; clinical factors include mental disorder and substance abuse; and historical and contextual factors involve past experiences (including being a victim of violence), 75 social interactions and support networks. 76 Serious mental illness is associated with an increased risk of violence: for example, 2% of the general population reported committing acts of violence over a 12-month period, compared with 8% of people with schizophrenia, 10,71 and rates are higher in individuals with recorded cannabis abuse or dependence (19%) or alcohol abuse or dependence (25%). The risk of violence in people with serious mental illness such as schizophrenia has consistently been shown, using different study designs in different settings, to be elevated by substance use. 71,77-79 Evidence from a Swedish cohort suggests that the risk of violence is 'minimal' in people with schizophrenia without co-morbid substance use; it is only the presence of substance misuse that increases the risk of violence.80 Therefore mental illness alone is not a reliable predictor of violence, and more research is required on the contextual and situational factors that precede the violent incident.

#### **Detection of violence risk in patients**

Mental health services have a duty to prevent violence by treating the clinical needs of the patient while protecting the public and ensuring staff safety. The Department of Health's guidance on best practice in the assessment and management of risk identifies the main risk factors for violence and advocates the use of structured professional judgement tools. The guidance also emphasises that training in risk management should be updated at least every three years. 81,82 The Royal College of Psychiatrists' report Rethinking risk to others in mental health services stresses the difficulty of risk prediction, particularly for rare events such as homicide. However, good risk assessment is necessary to inform clinical decisions and assist in the formulation of risk management plans, which are essential for providing appropriate care and treatment. The report stresses that 'what works best in reducing risk are personalised intensive services, with good communication between them. The lack of services for people in crisis has been highlighted as contributing to violence and homicide.'82

Engaging high-risk groups such as mentally ill offenders with mental health services, particularly following discharge from prison, has been recognised as an area of concern.<sup>83</sup> Diverting offenders from the criminal justice system into health and social care is a mechanism aimed at improving access to services. This does not just apply to prisoners: offenders can also be diverted to psychiatric services before arrest by the police or prior to prosecution. A recently announced £25 million government pilot scheme will provide funding for mental health nurses to be based in police stations or

courts. The intention is to quickly divert mentally ill offenders into the appropriate treatment, which will reduce their risk of reoffending.<sup>84</sup> This is a key component of the Government's policy 'Making mental health services more effective and accessible'.<sup>85</sup>

The rapid growth in the secure services population in recent years illustrates the increasingly important role that forensic services have in accommodating and treating individuals diverted from prison, from courts, or referred by community mental health teams. However, there is currently limited evidence of the efficacy of court diversion and its impact on outcomes such as recidivism (specifically violent reoffending) or improvements in mental state compared with patients admitted from the community.<sup>86</sup> More research is required to determine whether mentally disordered offenders have improved outcomes if they access services via the court diversion scheme compared with other pathways. Further research is also required to determine which offenders with mental disorders or learning disabilities should be diverted.

By whatever route mentally disordered offenders come into contact with services, ensuring that they engage in treatment and stay well is crucial to reducing the risk of a relapse into violence. Yet those most in need of care, for example patients with personality disorders, may refuse to engage in treatment and are commonly difficult to manage. Patients may also lack insight into their illness and/or have had previous negative experiences of mental health services due to ward environment, involuntary admission, negative attitudes from healthcare staff or compulsory treatment; they may subsequently refuse treatment. Guidance on working with offenders with personality disorder has been produced by the Department of Health and the National Offender Management Service, which provides practical support and advice on managing people with personality disorder in the community who present a high risk of violence.87

#### **Interventions**

There is limited evidence on effective treatments that reduce the risk of violence, but Cullen et al. (2011) recently demonstrated that the use of a cognitive skills programme resulted in an improvement in social cognitive skills and a reduction in violence and antisocial behaviour.88,89 Modifiable risk factors for violence perpetrated by patients with psychosis include substance misuse and non-adherence to psychological therapy and medication.90 More research is required to determine the causal associations of risk factors on violent behaviour, the predictive validity of risk assessments and the efficacy and acceptability of risk management plans for service users. 91 There is evidence that identification of early warning signs and relapse prevention can be effective in reducing the number and severity of violent incidents.92 Further research is required to identify more clinically effective treatments, and to determine what works for different patient groups.

### Authors' suggestions for policy

- Experiencing violence can be an important risk factor for perpetrating violence: therefore reducing experiences of violence as a child and an adult may be an effective way of reducing the perpetration of violence.
- Violence against people with mental illness is common but has often not been adequately identified or addressed by the healthcare system. For example, it is thought that health professionals only identify domestic abuse in 10-30% of those who present with a mental illness and are subject to domestic abuse.
- Primary and secondary healthcare staff need training, including awareness that people with mental health problems have a two to tenfold risk of being a victim of violence compared with the general population (with a higher risk for more severe illnesses), and that there are gender differences in the types of violence experienced. They also need guidance on identifying victims of violence sensitively and in a non-judgemental way; this includes believing the patient, safety planning to prevent repeated violence, multi-agency working and evidence-based interventions to avoid the adverse impacts of violence on mental health (see NICE guidelines, PH50 'Domestic violence and abuse: how health services, social care and the organisations they work with can respond effectively', issued February 2014).
- Clinicians should continually update their training in the use of structured professional judgement tools, risk formulation and management within the context of personalised care. This should be a key feature of psychiatric training and continued professional development.
- Substance misuse, particularly excessive alcohol consumption, is a major contributor to violence in the community. A public health approach to reduce hazardous levels of drinking is required.
- People with mental health problems may be deterred from accessing mental health services due to the stigma attached. This is an important public health issue which should be recognised and addressed.
- Improvements to the care and treatment of patients with serious mental illness and co-morbid substance dependence/misuse may reduce violence by patients.
- More research is needed into clinical interventions to reduce the experience of being both a victim of violence and a perpetrator of violence, to identify what works for specific patient groups.
- Commissioners should ensure that joint strategic needs assessments include the mapping of services to address violence experienced by both children and adults, and develop referral pathways that aim to meet the health and social care needs of all those affected by violence.

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# Chapter 15

# Suicide and self-harm

#### **Chapter authors**

Keith Hawton<sup>1</sup>, David Gunnell<sup>2</sup>, Navneet Kapur<sup>3</sup>

- 1 Professor of Psychiatry and Director of the Centre for Suicide Research, Department of Psychiatry, University of Oxford
- 2 Professor of Epidemiology, School of Social and Community Medicine, University of Bristol
- 3 Professor of Psychiatry and Population Health and Head of Research, Centre for Suicide Prevention, Centre for Mental Health and Risk, University of Manchester

### Key statistics

- A total of 4,513 suicides were recorded in England in 2012. The incidence was more than three times higher in males than females (12.4 vs 3.7 per 100,000) in 2010-2012.¹
- Suicide rates were at their lowest recorded levels in England in 2006/07.² Since then, they have increased slightly (by 4%), most likely due due to the impact of the economic recession.¹
- Approximately 28% of people who die by suicide have been in contact with mental health services in the previous year, and for half of these the last contact was within a week of death.<sup>3</sup>
- The main method of suicide in England is hanging (60% of male and 38% of female suicide deaths in 2012); the use of this method is increasing in both males and females.¹
- There has been a year-on-year rise in suicides by helium gas inhalation over the last 5 years.¹
- High-risk groups for suicide include men aged 35-54 years¹ and people who have self-harmed, have depression, misuse alcohol, are facing economic difficulties, are going through divorce or separation, or have long-term physical illnesses.⁴
- Rates of self-harm per 100,000 in 2011 based on hospital presentations in the Multicentre Study of Self-harm in England were 443 in females and 344 in males, which equate to approximately 245,000 hospital presentations in England per year.<sup>5</sup>
- Some 6-10% of adolescents in the community report having self-harmed in the previous year, yet of these only about one in eight report having presented to clinical services.<sup>6</sup>

#### Overview

Suicide and self-harm are adverse health outcomes which may occur in relation to a range of mental health problems and difficult life circumstances. Critically, self-harm (nonfatal intentional self-poisoning or self-injury, irrespective of degree of suicidal intent or other motivation) is a key risk factor for suicide; at least half of people who die by suicide will have engaged in self-harm at some stage in their lives, often shortly before death. The risk of suicide following self-harm is some 60-100 times the risk of suicide in the general population in the first year after self-harm.

Nevertheless, self-harm is far more frequent than suicide, with approximately 30-40 hospital-presenting episodes of self-harm for each suicide, but this ratio is much lower in older people (less than 10 to one). Increasingly, researchers and clinicians tend to talk in terms of the suicidal process, which incorporates the development of suicidal ideas, and then non-fatal self-harm, and ending, in some cases, with suicide. Most prevention and intervention initiatives are common to both suicide and self-harm.

# Suicide and self-harm as outcome measures

Although suicide may be used as an outcome measure in mental health services, there are issues with this. First, as discussed below, both suicide and self-harm are behaviours with multiple causes, several not directly related to mental health. Psychiatric disorders might well be present, especially in people who die by suicide, but such individuals may not have been in contact with clinicians – especially mental health practitioners. Secondly, suicide fortunately remains quite a rare outcome; in this respect, self-harm might be more useful as an indicator. However, currently there are not robust systems for recording self-harm accurately at a national level. Thus while safety-related outcomes such as suicide and self-harm are of great importance, there are several other important outcome indicators.

### Recent trends in suicide

#### **National data**

There were 4,513 suicide deaths recorded in England in 2012. The 3-year average (2010–2012) rate was 8.0 per 100,000. Incidence was three times higher in men than women (12.4 vs 3.7 per 100,000). Suicide peaks in middle age: its incidence in 40–54-year-old men and women was approximately 23 per 100,000 and 7 per 100,000 respectively. Half of all suicides occurred in men aged under 55 years. Suicide is rare under the age of 15 years, and its incidence in 15-19 year olds is around a quarter of that seen in 40-54-year-olds.<sup>1</sup>

Suicide rates in England declined from the beginning of the century to their lowest recorded levels in 2006/07. Since then, they have increased by approximately 4%, most likely due to the impact of the recent economic recession.¹ However, a growth in use of narrative and accidental verdicts by coroners for possible suicides may have resulted in an underestimation in suicide rates of up to 6% in 2009;¹² this means that the impact of the recession on suicides is likely to have been underestimated. Variation between coroners in their use of different verdicts may distort comparison of suicide rates in different localities.¹³

The main methods of suicide in England currently are hanging (60% of male and 38% of female suicides) and self-poisoning (14% of male and 38% of female suicides).¹ Hanging is increasing in both genders, whereas self-poisoning deaths are falling.¹ There have been year-on-year rises in helium suicides in the last 5 years, with 51 helium deaths recorded in 2012.¹ Changes in the availability of commonly used, high lethality suicide methods may have a strong influence on overall suicide rates, and restricting access to lethal methods is a key component of prevention strategies.¹⁴ Reductions in suicide over the last 15 years have been in part due to a decline in car exhaust poisonings following the introduction of catalytic convertors.¹⁵ Approaches to

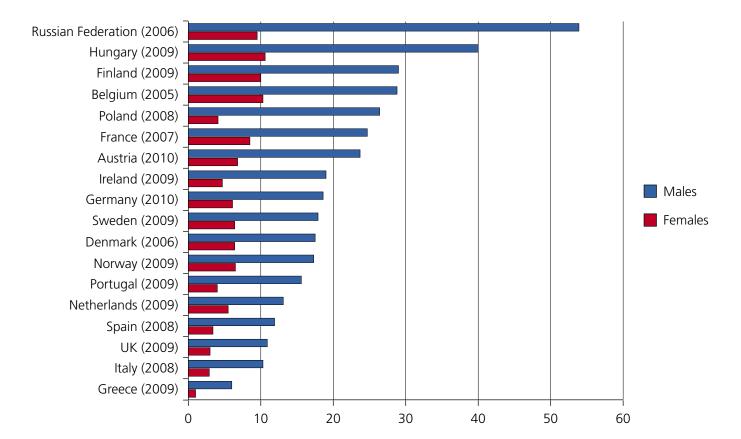


Figure 15.1 Suicide rates in selected European countries per 100,000 population

Source World Health Organization, 2014 (using latest year available).

reduce the incidence of suicide by hanging are particularly challenging, but could include limiting media portrayal of this method as a quick and easy method of suicide.<sup>16</sup>

Data from the World Health Organization (WHO) indicate that the incidence of suicide in the UK is lower than in many other high-income countries (see Figure 15.1).<sup>17</sup> Differences between countries are most likely due to a combination of factors, including levels of alcohol misuse, the lethality of commonly used methods of suicide, economic prosperity, religious and cultural attitudes towards suicide, and access to treatment. They will also be influenced by variations in the procedures and level of evidence required in ascertainment of suicides.

## Suicide among people in contact with psychiatric services

The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness, a UK-wide study of people who have had contact with psychiatric services in the 12 months before their death, provides information on suicide in specialist mental health care settings.<sup>3</sup> Currently there are 1,200-1,300 suicide deaths among psychiatric patients per year in England, representing around 28% of all suicides. Of those people in contact with psychiatric services, half had been seen in the week before death.<sup>3</sup>

# Suicide in people not in contact with psychiatric services

Approximately three-quarters of people who die by suicide are not in current or recent contact with psychiatric services at the time of death.<sup>3</sup> A greater proportion of males than females come into this category. 18 Otherwise, the characteristics of individuals in this group largely reflect those of people who die by suicide in general. Prevention will largely necessitate general population rather than servicerelated initiatives (e.g. restriction of access to means for suicide, population approaches to prevention of depression, improved detection and management of psychiatric disorders in primary care, and voluntary agency and internet-based support). 19 There will be other individuals whose deaths are not recorded as suicides who will nonetheless have actively and intentionally contributed to their deaths through, for example, chronic alcohol misuse and failure to take prescribed medication.

#### Recent trends in self-harm

Based on findings from the Multicentre Study of Self-harm in England, which collects data on incidence of all hospital-presenting self-harm in five hospitals in Oxford, Manchester and Derby, <sup>20</sup> the incidence of self-harm in 2011 was 340 per 100,000 in males and 440 per 100,000 in females. These figures indicate that there may be as many as 245,000 self-harm presentations to hospitals in England each year.<sup>5</sup>

Figure 15.2 Age-standardised rates of self-harm in people aged 15 years and over in three centres (Oxford, Manchester and Derby), combined

Source Unpublished data from the Multicentre Study of Self-harm in England

#### **Box 15.1 Key policy documents**

Several major policy documents regarding suicide and self-harm are available:

#### The National Suicide Prevention Strategy for England and annual updates

These documents give details of key policies and interventions that may help to reduce suicide.

#### National Institute for Health and Care Excellence (NICE) guidelines: Self-harm: shortterm management, Self-harm: longer-term management and evidence updates

These are evidence-based clinical guidelines for professionals involved in the management of people who self-harm.

### NICE quality standards and guidance for commissioners

Based on the clinical guidelines, quality standards identify the key markers of high-quality self-harm services. The accompanying guidance is for those seeking to commission such services.

# Reports from the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness

These reports focus on specialist mental health settings and include annual reports of suicide trends, as well as topic-specific reports – for example primary care and service configuration.

Rates of self-harm in England decreased in parallel with suicide rates from the beginning of the century until 2007;<sup>21</sup> then, like suicide, they increased in some areas following the onset of the recent economic recession, particularly in males (see Figure 15.2).<sup>5,22</sup> Rates are generally higher in females

than males, especially among adolescents, and decrease with age. Peak ages for self-harm are 15-24 years in females and 20–29 years in males.<sup>21</sup> The majority of self-harm episodes presenting to general hospitals involve self-poisoning (especially with analgesics and psychotropic drugs), but presentations for self-injury have recently increased.<sup>5</sup>

Hospital Episode Statistics (HES) record data on episodes of self-harm that result in admission to hospital. This is potentially problematic, as only just over half of hospital presentations result in admission, and this proportion varies fourfold between hospitals.<sup>23</sup>

#### Causes of suicide and self-harm

A wide variety of factors can contribute to suicide and self-harm (see Figure 15.3). <sup>24,25,26</sup> These include distal factors (e.g. genetic influences, family history and early trauma) and proximal factors (e.g. psychiatric disorder, physical illness, relationship breakdown and other life events). Changes in socio-economic environment are important, as is exposure to suicidal behaviour by others, including through the media. Availability of suicide methods can contribute to risk, and the danger of the method will partly determine whether an act is fatal or non-fatal.

### Prevention activities in England

#### **Suicide prevention**

Suicide prevention activity in England is informed by the priorities of the National Suicide Prevention Strategy,<sup>4</sup> which is overseen by the National Suicide Prevention Advisory Group (NSPAG). NSPAG works in collaboration with the National Suicide Prevention Alliance. NSPAG draws on experts from across the charitable and public sector and includes people bereaved by suicide. Many local areas have developed multi-

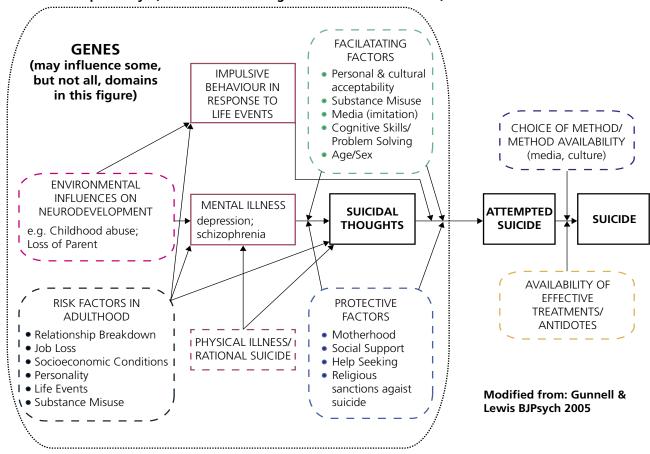


Figure 15.3 Causal pathways (factors contributing to suicide and self-harm)

Source Modified by Keith Hawton from Gunnell D, Lewis G. Studying suicide from the life course perspective: Implications for prevention. British Journal of Psychiatry. 2005;187:206-8.

agency suicide prevention groups; however, according to a report from the All-Party Parliamentary Group on Suicide and Self-Harm Prevention, this is patchy.<sup>27</sup>

In addition to the National Suicide Prevention Strategy, there have been several positive specific developments in relation to suicide prevention in England in recent years.<sup>28</sup> These include support of the research in this field by the National Institute for Health Research.<sup>29</sup>

#### Public health and local authority policies

It is increasingly apparent that suicide prevention in geographical areas must have sound backing from local authorities, including public health. Such agencies can provide the stimulus for important local initiatives and their evaluation (see Case study 1). The priorities of local service commissioners will also be of considerable relevance to suicide prevention, including, for example, commissioning of:

- dedicated self-harm services that seek service user feedback, have training in place for professionals, provide access to good quality assessment and treatment, provide separate services for young people, and give care in physically safe environments;<sup>30</sup>
- provision of high-quality mental health services that are compliant with recommendations from the National Confidential Inquiry (see below);
- alcohol and drug services.

#### Mental health services

Data from the National Confidential Inquiry suggest that mental health services are becoming safer. Psychiatric admission is a period of heightened suicide risk.<sup>34</sup> Prevention initiatives have focused on general improvements to care, removing noncollapsible rails (which could be used as ligature points) and reducing absconding (e.g. by improving the ward environment and better supervision of entry and exit points). These changes were associated with a 30% reduction in the rate of psychiatric inpatient suicide over a 10-year period, with big falls in hanging on the ward and suicide deaths after absconding.<sup>35</sup> However, there is some evidence that rates of suicide in the immediate post-discharge period may have increased.<sup>3</sup>

A large study across England and Wales showed that services that implemented National Confidential Inquiry recommendations to improve the safety of specialist mental health services had a lower suicide rate than services that did not.<sup>36</sup> Three recommendations in particular were associated with a lower suicide risk, namely: 24-hour crisis services; having a policy for patients with dual diagnosis (drug and alcohol problems in combination with mental illness); and multidisciplinary reviews after suicide. Together these service changes may have been associated with between 200 and 300 fewer deaths per year.

# Box 15.2 Case study 1 – a public health intervention at a local suicide hotspot in Bristol

Bristol's Suicide Prevention and Action group is a partnership between Bristol City Council, the NHS (liaison psychiatry, mental health trusts, GPs, commissioners and pharmacy advisers), Bristol University, local police and ambulance services, Network Rail, Samaritans and other voluntary sector groups.

The group have been working for many years on reducing suicide from local suicide hotspots, in particular Clifton Suspension Bridge. Local research helped to inform the Clifton Suspension Bridge Trust's decision to investigate the feasibility of installing protective barriers on the bridge, a task made more difficult by the fact that the bridge is a listed building of major historical importance. Protective barriers were the preferred intervention because there is good research evidence to suggest that restricting access to means can prevent suicide; furthermore, there was already Samaritans signage and surveillance by cameras on the bridge, which is manned 24 hours a day by two or more members of bridge staff.

Barriers were put in place in 1998, paid for by the Clifton Suspension Bridge Trust. Evaluation of the impact of these barriers indicates that they have prevented more than 60 suicides by jumping (1998-2012): deaths from the bridge declined from eight per year (1994-98) to three per year (2008-11), and have not declined further. Some 90% of suicides from the bridge involve males. An evaluation of the impact of the barriers found no evidence of an increase in male suicide by jumping from other sites in the Bristol area after the erection of the barriers.<sup>31</sup>

The group meets the suspension bridge's bridgemaster every year to discuss how to further reduce deaths from the bridge as well as the NHS aftercare of people who are prevented from jumping. The local Samaritans offers support and training to bridge staff who have witnessed distressing events and to help them respond to suicide attempts. Bristol's Suicide Prevention and Action group has worked closely with local media organisations to reduce reporting of deaths from the bridge and for any suicide reporting to follow Samaritans' media guidelines. Recent evaluation of this showed that reporting had declined from 2.8 reports per suicide in the 1970s to 0.7 per suicide in the 2000s,<sup>32</sup> and an audit of reporting over a year indicated that regular dialogue with newspaper editors did have an effect on the tone of reporting.33

# Box 15.3 Case study 2 – care of people who frequently self-harm

People who repeatedly self-harm have a high level of psychological morbidity and risk of suicide. Clinical indicators of borderline personality disorder (BPD) may be present and, in the absence of concomitant mental illness, this vulnerable population frequently does not 'fit' with conventional mental health services or feel able to engage with specialist personality disorder teams. Emergency departments (EDs) and mental health services are usually ill-equipped to meet the complex needs of these patients, who consequently often feel let down and uncared for, heightening their risk of self-harm.

A 25-year-old young woman with a diagnosis of BPD who was not formally engaged with mental health or personality disorder services was presenting with increasing frequency to the ED at the John Radcliffe Hospital in Oxford following self-harm. While she found the psychosocial assessments she received from the self-harm team helpful, their benefit was limited in that they were in response to self-harm and were thus reactive, and were not always undertaken by regular staff, therefore risking inconsistency in approach.

To offer this young woman more continuous care with the intention of reducing her self-harm, improving her wellbeing and providing alternatives to regular use of emergency services, fortnightly outpatient appointments were offered over the course of a year with consistent members of the self-harm team. Sessions were collaborative, within agreed boundaries, and were problem focused. The approach used was underpinned by principles of transactional analysis, psychodynamic theory and learning theory. The self-harm practitioners received supervision from the personality disorder service.

Over the year, admissions to ED and contact with police, paramedics and crisis teams were significantly reduced, and the patient said that she felt supported and stabilised.

Based on the apparent value of this simple approach, a wider outpatient service, Brief Interventions in Repeat Self Harm (BIRSH), supported by the Foundation of Nursing Studies, has been established for people who present to the ED with repeat self-harm or who are assessed to be at risk of repeating self-harming behaviours. The focus is on facilitating self-efficacy with regards to problem solving and managing self-harming behaviour. Systematic outcome measures are used to enable evaluation of BIRSH and identify areas for future development.

There continues to be controversy about the extent to which physical treatments for mental disorder prevent suicide, but emerging evidence indicates that antidepressants may be beneficial,<sup>37</sup> especially in elderly people, and that lithium reduces suicide risk,<sup>38</sup>

#### **Service for self-harm patients**

While services for self-harm patients remain variable, the situation seems to be improving. A recent study carried out across England found that nine out of 10 hospitals have specialist teams for the assessment and management of self-harm.<sup>23</sup> Examples of high-quality services include nurse-led teams that have built up expertise and collaborative links over a number of years, fulfil a wider education function and, in some cases, offer evidence-based psychological intervention.

Encouragingly, there is now evidence that brief psychological treatment (cognitive behavioural therapy/problem solving) may reduce repetition of self-harm.<sup>39</sup> Individuals who are frequent repeaters of self-harm present particular challenges, but successful care could have major benefits not only for the individuals themselves but also for reducing demands on services (see Case study 2).

#### **Prisons**

Several measures have been introduced in prisons to try to reduce suicide and self-harm, including safer cells and the Assessment, Care in Custody and Teamwork (ACCT) procedures for prisoners at risk of self-harm.<sup>40</sup> Encouragingly, the numbers of prison suicides in England had declined from the peak of a few years ago (95 in 2003 to 52 in the year up to March 2013<sup>41</sup>), but in the most recent figures have showed a marked upturn (88 in the year up to March 2014)\*. Self-harm episodes by female prisoners have recently decreased from what were very high levels<sup>42</sup> (5,970 in 2013 compared with 13,361 in 2005), probably related to diversion of individuals who are high repeaters of self-harm to other settings. However, episodes of self-harm in male prisoners have increased (17,213 in 2013 compared with 10,420 in 2005).41 Current initiatives to enable closer working between police and mental health staff should contribute to diversion of some individuals with psychiatric disorders away from prison to more appropriate treatment facilities.43

### Restriction of access to methods of suicidal behaviour

The effectiveness of restriction of access to methods of suicidal behaviour has been demonstrated recently by the impact of withdrawal of the analgesic co-proxamol,<sup>44</sup> which has resulted in considerable reduction in suicides involving analgesics; the beneficial effects of smaller packs of paracetamol;<sup>45</sup> and the introduction of a safety barrier on Bristol's Clifton Suspension Bridge.<sup>31</sup>

#### Media influences on suicidal behaviour

Samaritans has for several years been monitoring new media reports and portrayals of suicides and giving feedback to editors and producers where media guidelines<sup>46</sup> have not been followed (see Box 15.4).

#### People bereaved by suicide

There has been far greater recognition of the needs of people bereaved by suicide, including a special action area in the National Suicide Prevention Strategy.<sup>4</sup> Although services for the bereaved remain limited, mainly relying on self-help organisations, useful, easily accessible resources have been made freely available, including the booklet *Help is at Hand*<sup>47</sup> and a HealthTalkOnline website on bereavement by suicide.<sup>48</sup>

# Box 15.4 Case study 3 – working with the media to improve portrayal and reporting of suicide

Samaritans has been working closely with the media for two decades, providing expert advice on how to portray suicide responsibly through its media guidelines. This is because extensive research demonstrates strong links between media portrayal of suicide and imitative behaviour among vulnerable people. Samaritans works with all members of the media, from mainstream news reporting to documentaries, soaps, virals and advertising.

In October 2012, Channel 4's youth drama series *Hollyoaks* approached Samaritans with a suicide storyline. Teenage character Esther was to make a suicide attempt by taking an overdose of paracetamol. Samaritans worked with the producers, advising them on the scenes. They consulted with experts in the field and referred to published research demonstrating the dangers of naming a drug used in an overdose. This was particularly important in the case of *Hollyoaks*, as this programme attracts a young audience, and young people are particularly vulnerable to media influences.

Fortunately the producers of *Hollyoaks* followed this advice and handled the portrayal of the suicide attempt extremely carefully. The episodes covering the suicide attempt were accompanied by online support, including a video from Esther, encouraging viewers to seek help if they experience suicidal feelings. Anecdotal evidence has shown that some callers to Samaritans' helpline referred to the storyline and spoke of experiencing similar feelings to Esther's. Other helplines also reported an increase in calls.

Suicide is clearly a very challenging topic and, if handled sensitively, the media – across all genres – can play an important role in helping to raise awareness of the issues, promote help-seeking behaviour and signpost sources of support. Local suicide prevention plans should include working with local media.

<sup>\*</sup> See: https://www.gov.uk/government/uploads/system/uploads/ attachment\_data/file/339067/safety-in-custody-to-mar-2014.pdf

### Authors' suggestions for policy

#### National data on suicides

In order to accurately monitor trends in suicides and the effectiveness of prevention initiatives, it is essential that good quality information on suicides is available through coroners and from the Office for National Statistics (ONS). Continuation of the policy of coroners operating criminal levels of evidence in order to reach suicide verdicts and the increasing use of narrative verdicts contribute to underestimation of the true levels of suicide.<sup>13</sup>

#### Responses to economic challenges

The recent global economic recession has had a major effect on suicide, particularly in European males. <sup>49</sup> Responses of governments in terms of labour and welfare policies in times of economic downturn may affect the health of national populations, especially suicide. <sup>50</sup> Thus large differences between countries in the impact of unemployment on suicide appear in part to be explained by differences in spend on active labour market programmes and welfare programmes. <sup>51</sup>

#### Mental health services

There has been real progress in suicide prevention in psychiatric inpatient units, but settings that are alternatives to inpatient care (e.g. crisis resolution and home treatment teams) also need to be considered. The National Suicide Prevention Strategy for England highlights the importance of accessible high-quality services in preventing suicide. Specific service-related initiatives seem to have had an effect, but mental health services, EDs and primary care all play an important role. The impact of future mental health service changes on patient suicide should be reviewed.

People who die by suicide may be at least as likely to have been in contact with police as mental health services in the months before death.<sup>52</sup> The recent development of an Association of Chief Police Officers' national suicide prevention policy is therefore very welcome. Closer working between police and mental health clinicians is likely to enhance suicide prevention.

#### **Services for self-harm patients**

Standards of hospital services for self-harm patients vary. For example, despite a clear recommendation from NICE in 2004 that all self-harm patients should receive a psychosocial assessment of needs and risk, in a study of a representative sample of 32 hospitals in 2010/11 in England, only 57% of patients received such an assessment.<sup>23</sup> Ways need to be found of increasing the proportion of self-harm patients receiving a psychosocial assessment in hospital. An overreliance on 'risk scales' – brief checklists of symptoms or characteristics – is unlikely to be helpful because of the poor predictive value of most instruments.<sup>53,54</sup> Instead, patient risk should be considered alongside patient need in a comprehensive psychosocial assessment.

Services should have ready access to brief psychological therapy following discharge for patients for whom it is suitable.<sup>30</sup> Patients who are multiple repeaters of self-harm require special attention,<sup>55</sup> with further development of effective therapies. The high levels of alcohol misuse and subsequent alcohol-related deaths in self-harm patients<sup>56</sup> necessitate screening for alcohol misuse in those who self-harm and availability of alcohol services in general hospitals to offer treatment. Another challenge regarding hospital care of self-harm patients is the need to develop training that can help counter the often negative attitudes and understanding of general hospital medical and nursing staff regarding self-harm,<sup>57</sup> which may badly affect the experiences of service users.<sup>58,59</sup> Above all, commissioners of services should place high priority on having effective local services.

#### Young people

Given the extent of self-harm in young people, including in community populations of adolescents not presenting to clinical services,<sup>6</sup> attention should be paid to treatment and prevention. This issue is compounded by the increasing role of the internet and other media influences on suicidal behaviour in young people, including possible negative influences of some social networking sites and the toxic effects of cyber-bullying.<sup>60</sup> Prevention may be most feasible through school-based mental health promotion programmes and regulation to restrict or remove internet sites that clearly encourage suicidal behaviour. Novel intervention initiatives might harness the power of the internet and smartphones to provide readily available advice, support and therapy, such as through apps and internet-based treatments that focus on distressed and suicidal young people.<sup>61</sup>

## Tracking novel and increasing methods of suicidal behaviour

There is growing evidence that the rise in use of a new method of suicide – if it is readily available and of high lethality – can lead to increases in the incidence of suicide. 62 For example, in the last 15 years there has been an epidemic rise in the use of charcoal burning (particularly in Hong Kong, Taiwan, Korea and Japan) as a method of suicide; these increases are associated with rises in suicide rates in some of these countries. 63 Media (news and internet) reporting of high-profile deaths using these methods is thought to have triggered these epidemics.<sup>64</sup> It is therefore essential that UK policy makers work closely with the media and internet service providers to avoid dramatic reporting and provision of detailed information about methods, to reduce the risk of a similar phenomenon occurring here. Likewise, it is important that surveillance systems are put in place to identify any rise in suicides using these novel methods at as early a stage as possible, to ensure that effective public health action may be taken to restrict access to these methods.<sup>62</sup> The rise in helium suicides is a recent concern in the UK.1

#### Physical illness and suicidal behaviour

Several physical disorders are associated with increased risk of self-harm and suicide, <sup>65-67</sup> with depression being a major mediating factor. <sup>65</sup> This highlights the need for improved integration of physical and mental health healthcare, education of GPs and physicians about warning signs (e.g. depression or hopelessness) and greater attention of mental health practitioners to the physical health of their patients.

# International collaboration in development of improved knowledge and prevention policies

Many of the issues that challenge prevention and treatment of suicidal behaviour in England are common problems in other countries. Increased collaborative research at international level is likely to be highly advantageous. This might include multi-national evaluation of treatment and prevention initiatives. The forthcoming WHO global suicide report (to be published in September 2014) could be an important step in this direction, along with activities of other national<sup>68</sup> and international organisations that focus on suicide prevention.<sup>69</sup>

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## Chapter 16

# Addictions, dependence and substance abuse

#### **Chapter authors**

John Strang<sup>1,2</sup>, Colin Drummond<sup>3,4</sup>, Ann McNeill<sup>5,6</sup>, Malcolm Lader<sup>7</sup>, John Marsden<sup>8,9</sup>

- 1 Professor of Addictions and Director, National Addiction Centre, Institute of Psychiatry, King's College London
- 2 Leader of Addictions Clinical Academic Group, Kings Health Partners Academic Health Sciences Group, London
- 3 Professor of Addiction Psychiatry, National Addiction Centre, Institute of Psychiatry, King's College London
- 4 Clinical Director for Alcohol, South London Health Innovation Network
- 5 Professor of Tobacco Addiction, National Addiction Centre, Institute of Psychiatry, King's College London
- 6 Deputy Director, UK Centre for Tobacco and Alcohol Studies, Nottingham
- 7 Emeritus Professor of Clinical Psychopharmacology, National Addiction Centre, Institute of Psychiatry, King's College London
- 8 Professor of Addiction Psychology, National Addiction Centre, Institute of Psychiatry, King's College London
- 9 Senior Academic Advisor for the Alcohol, Drug and Tobacco Division, Health and Wellbeing Directorate, Public Health England, London

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# Key statistics

### Alcohol

- Alcohol is now the third leading preventable cause of ill health in Europe, after smoking and hypertension, and is the leading preventable cause of morbidity and mortality in working age adults.<sup>1</sup>
- Alcohol consumption in England has doubled in the last 60 years, with a fivefold increase in deaths from alcoholrelated diseases such as liver cirrhosis.<sup>2</sup>
- Alcohol-related hospital admissions in England have doubled in the last 9 years.<sup>3</sup>
- In 2007, over 1.6 million adults in England were alcohol dependent, but a national needs assessment showed that only 6% of people with alcohol dependence access treatment each year).<sup>4</sup>

### **Tobacco**

- Over the last 60 years, smoking in England has declined dramatically from approx. 80% (m) and 40% (f) in the 1950s now down to <20% for the first time since surveys began.<sup>5</sup>
- Smoking is still the largest single cause of death and disease in England, killing over 79,000 people in 2011.6
- Smoking is the primary driver of health inequalities in England.
- Recent evidence suggests that mental health improves on stopping smoking,<sup>7</sup> in addition to the physical benefits.

### **Opiates**

- Globally, 12–21 million individuals are addicted to heroin; this equates to 9.2 million disability-adjusted life years (DALYs).
- In England in 2011/12 there were 8.4 opiate and/or crack cocaine users per 1,000 general population,<sup>8</sup> and 155,000 people in treatment for opiate addiction.
- One in three members of the English prison population has a history of heroin use and dependence (compared with less than 1% of the general population).<sup>9–11</sup>
- Heroin/opiates contribute disproportionately to deaths: they are responsible for more than 50% of all drug overdose deaths in England.<sup>12</sup>

## **Benzodiazepines**

- Benzodiazepine usage can be:
  - therapeutic dose prescribing less than 30 mg of diazepam daily (or equivalent)
  - doses above the licensed limits
  - high doses, misused either alone or as part of polydrug abuse.
- About 10% of long-term users (users for more than 3 months) are physically dependent, with a characteristic

syndrome on withdrawal. Up to a third of high-dose and longer-term users are at risk. Withdrawal problems have been known since the 1970s and official warnings have been issued, but high prescribing levels continue.

# Commissioning: understanding the problem and the diversity of need

This chapter addresses addiction to/dependence on drugs (licit/illicit, medicines and other products) with dependence potential and abuse liability, where key evidence-based recommendations for action can be identified. Not all possible substances are covered, but the approach taken illustrates relevant analysis for other drugs too. Needs assessment defines healthcare need as the 'ability to benefit'.<sup>13–15</sup> We consequently examine alcohol, tobacco, drugs (with special attention to heroin/opiates) and benzodiazepines.

### Dependence and associated harms

Different types of substances cause harm in different ways, over varying time periods. For alcohol, there is long-term harm from chronic exposure (e.g. liver damage and cirrhosis), as well as serious harm to self and others from acute intoxication (e.g. road traffic accidents, violence, injuries).4 For tobacco, the main health implications are not nicotine dependence per se but the associated major long-term harms of smoke exposure (e.g. lung cancer, heart disease)<sup>16</sup> and also the harm, particularly to children, caused by passive smoking. For opiates, there are acute toxic harms (including overdose deaths) and also long-term harms from associated behaviours affecting both self and others (e.g. infection from and transmission of HIV and hepatitis C from needle-sharing, involvement in crime).<sup>17</sup> For benzodiazepines, long-term health harms include impairment of cognitive functioning ('pseudodementia') and damage to driving ability. 18,19

# Benefits of behavioural change

At least three types of benefit from behavioural change can be identified:

- (a) substantial individual benefit from major change in behaviours (e.g. after major treatments);
- (b) widely dispersed population-level benefit from modest change in behaviours (e.g. after screening and brief interventions); and
- (c) indirect benefit to others e.g. reduced HIV transmission, reduced crime (see Table 16.1).

### Table 16.1 Behavioural change: types of benefit for different populations

# Substantial individual benefit from major change in behaviours

- inpatient and residential detoxification and rehabilitation
- nicotine replacement therapy, including nicotine gum, patches, etc, and other non-nicotine treatments to help smokers quit cigarette smoking
- opiate substitution treatment to enable those injecting heroin to quit
- peer-led mutual help organisations such as Alcoholics Anonymous and Narcotics Anonymous to support individuals to maintain sobriety

# Widely dispersed population-level benefit from modest change in behaviours

- brief intervention in general medical settings, widely delivered to populations including those only with a different reason for health contact, to trigger reduction or guitting of the relevant behaviour.
- hepatitis B vaccination programmes to prevent viral infection

### Indirect benefit to others

- reduced drink driving and harm to others; reduced domestic violence
- reduced harm to others via secondary inhalation of cigarette smoke
- needle and syringe exchange programmes to reduce sharing of needles and syringes and prevent transmission of HIV
- opiate substitution treatment to reduce levels of acquisitive crime and public nuisance
- hepatitis B vaccination to reduce transmission to others

# 'Duty of care', 'duty to detect' and 'duty to act'

Duty of care comprises both a duty to detect and a duty to act element.

Duty to detect requires a commitment to universal scrutiny for evidence of addiction problems – either as the presenting medical condition or from an opportunistic screening enquiry.

Duty to act applies to all medical practitioners, for all patients. Special attention is required when caring for disadvantaged populations, such as those with co-existing conditions, or in settings such as prisons or hostels.

Duty to detect and duty to act have important implications for planners of healthcare and provider organisations, as well as for all practitioners.

# 'Hard-to-reach', 'hard-to-treat' and 'critical-to-treat'

Attention to hard-to-reach populations is an essential component of the healthcare provision in a locality. Addiction problems are often more prevalent among these populations and may be complicating their condition.

Hard-to-treat patients and populations have not obtained the expected benefits from standard approved first-line treatments. More intensive or more complex treatments must then be delivered.

Critical-to-treat patients and populations crucially need effective treatment of their addiction for proper management of their other health conditions (e.g. addressing smoking after a heart attack or stroke, addressing alcohol in a patient with liver disease, addressing heroin addiction that co-exists with pregnancy).

Timely provision of Attention to treatment to 'hard-to-reach' Specialist 'critical-to-treat' populations treatment of individual patients 'hard-to-treat' More substantial interventions at primary and secondary care level Public policy initiatives and population-level brief interventions

Figure 16.1 Addressing hard-to-reach, hard-to-treat and critical-to-treat substance abusers

# Whole-society commissioning: multi-modality for diversity

Commissioners and clinicians must deliver preventive measures and active treatments of proven efficacy. With prevention and treatment, it is not a case of either/or: balanced provision is required. The National Institute for Health and Care Excellence (NICE) has developed technology appraisals, guidelines and quality standards. Some preventive and secondary treatments continue to be provided despite the absence of an evidence base, even when well-conducted studies have demonstrated a lack of effectiveness. This is not acceptable.

Effective commissioning requires a balance of provision across different forms of public health and individual treatment modalities. NICE gives key guidance. Individual patients differ – one size does not fit all. Different patients will need different interventions, and the same patient will need different interventions as they progress through care pathways. One constructive approach to comprehensive healthcare provision is through a co-ordinated local consortium of providers (see Box 16.1).

# Box 16.1 Consortium commissioning – the Lambeth/SLaM consortium model

- In Lambeth, the addictions group at SLaM (South London and Maudsley NHS Foundation Trust) functions as the contract lead for a multi-site, multiagency service, incorporating both NHS and third sector providers.
- Each of the partners works in an integrated arrangement and plays their own distinct part in a local care pathway. Advantages include:
  - allowing funding to flow to consortium partners via sub-contracting agreements
  - preserving local ownership of the service while creating fuller engagement with local commissioners
  - improving access, enabling individualised service user reviews and creating easier movement to less intensive services when users are ready
  - allowing service users to engage with existing support services and service users' networks
  - through the expertise of the consortium, supporting the development and maintenance of the knowledge base, capacity and competency of local community teams.

- Training and support are provided both formally and informally to all consortium partners.
- As contract lead, the local NHS addictions group:
  - co-ordinates all information/reporting requirements
  - uses a single electronic patient record, regardless of organisation or service
  - uses single governance systems that inform the administration of service user involvement (SUI), complaints, safeguarding, contingency planning, etc.
  - leads on reviews of all aspects of the quality of services to promote shared learning and service improvement, including service user feedback, The patient experience data information centre PEDIC outcomes, mock inspections, etc.
  - audits, ensuring fidelity to the contract and service model across all sites
  - prepares reports for internal performance meetings
  - prepares reports for contractual meetings
  - assists all services with communication planning and events, including local scrutiny committees, stakeholder groups, etc.
  - performance manages each service in line with the National Drug Treatment Monitoring System, Public Health England guidelines and local priorities
  - monitors and reviews standards with regards to the Care Quality Commission, compliance with Monitor, service user feedback, etc.
- As a lead provider, the local NHS addictions group seeks consensus between the partners (following open discussion and transparent working) before adopting decisions. When and where this is not possible, escalation procedures and exception guidance is available to the consortium.
- The overall result is better quality provision, more easily accessible care, more collaboration between providers and easier movement, where appropriate, for patients from one stage/pathway/provider to another.

The integration of wider mental health care with addictions care provision is particularly important. The separate commissioning of addiction services has led to loss of integration and reduced reference to NICE guidance. Alternatively, the commissioning of addiction services should be brought back to healthcare commissioning.

It is important that joint planning and provision exist between addiction services and various other healthcare areas – these include Accident & Emergency (A&E) (see Box 16.2), antenatal care, <sup>20,21</sup> liver units, <sup>22,23</sup> cardiac care, infectious diseases and sexually transmitted infections.

# Box 16.2 Special A&E/addictions integrated care acute alcohol pathway

- In response to continuing high numbers of alcoholrelated acute medical admissions and A&E attenders at King's College Hospital, a special pathway has been set up to transfer suitable patients straight to the specialist inpatient alcohol unit at the Maudsley Hospital.
- Patients who are alcohol dependent and in need of detoxification are identified in the A&E department and transferred for inpatient assessment and care, including a four-day alcohol detoxification once they are medically well enough. This provides patients with a safe detoxification, assessment, preliminary motivational work, an introduction to 12-step mutual-aid programmes and planning for a return to community addiction services.
- This pathway has improved the clinical management of high-need and high-cost frequent attender patients who represent a high burden for the acute trust and mental health trust community services.
- The pathway has been possible because of the collaborative links between the two NHS trusts, which are both part of King's Health Partners (an Academic Health Science Centre) and have developed a joint alcohol strategy. It has also supported other collaborative ventures between the trusts to improve the response to alcohol within the populations served by the hospitals.
- The funding for the pathway comes from the acute trust tariff, and is designed to produce benefits i.e. reduced lengths of stay and reduced readmissions of these patients. Unplanned discharges are rare and the pathway is highly rated by both patients and acute hospital staff.

# The scale of the problem and its health consequences

## Scale of the problem - alcohol

Alcohol is the third leading preventable cause of ill health after tobacco and hypertension. Among men of working age, alcohol is the leading cause of premature death. In England alcohol is consumed by 87% of the adult population, with 24% (33% of men, 16% of women) consuming alcohol in a manner potentially or actually harmful to health or wellbeing, and 4% alcohol dependent (6% of men, 2% of women). The toxic and dependence-producing effects of alcohol contribute to over 200 different diseases.

Despite public interest in the cardio-protective effects of alcohol at low levels in middle-aged men, for many diseases (e.g. liver disease and some cancers) there is no level of alcohol consumption that is risk free, with the risk of harm increasing steeply with increasing alcohol consumption.<sup>24</sup> In 2009, alcohol was estimated to be responsible for circa 15,400 deaths in England.<sup>3</sup>

Alcohol-related hospital admissions in England had more than doubled to 1,220,300 by 2011/12, including more than a doubling of admissions wholly attributable to alcohol.<sup>3</sup> Deaths from cirrhosis of the liver, an important indicator of population levels of alcohol-related harm, increased in England and Wales by a factor of five between 1950 and 2002, in contrast to reductions in most other European countries.<sup>2</sup> The trend has continued in more recent years (see Figure 16.2).

Alcohol contributes to over 200 different diseases, both communicable and non-communicable, producing both physical and mental damage<sup>26,24</sup> (see Table 16.2). Some are acute (occurring shortly after consumption of alcohol) whereas others are more chronic, requiring extended exposure to harmful levels of drinking, sometimes over many years.

Alcohol also contributes to wider social harms - absenteeism, unemployment, domestic violence, family breakdown, child maltreatment and public disorder. Excessive drinking is estimated to cost the UK economy £12.6 billion per annum,<sup>27</sup> £3.5 billion of which is incurred within the NHS.<sup>28</sup>

Figure 16.2 Trend in premature mortality (ages under 65) from chronic liver disease and cirrhosis, England and EU countries, 1980 to 2009

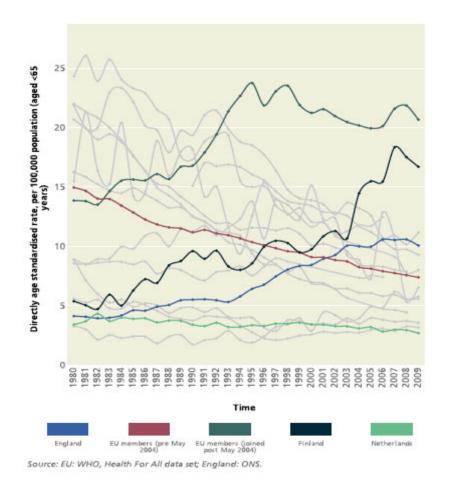
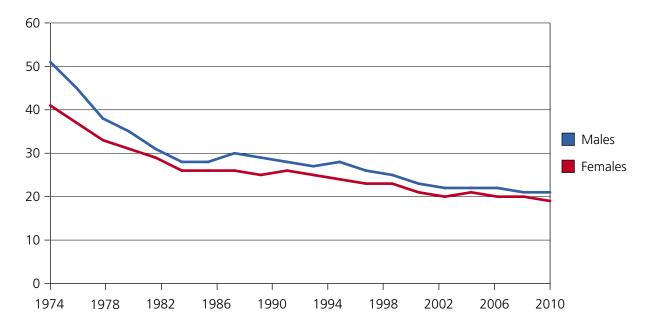


Table 16.2 Leading mental and physical disorders wholly or partly attributable to alcohol

	Wholly alcohol attributable	Partly alcohol attributable
Acute	<ul><li>ethanol poisoning</li><li>acute alcohol withdrawal</li><li>delirium tremens</li></ul>	<ul> <li>acute pancreatitis</li> <li>injuries</li> <li>falls</li> <li>road traffic accidents</li> <li>intentional self-harm</li> <li>suicide</li> <li>assault</li> </ul>
Chronic	<ul> <li>alcohol dependence</li> <li>alcoholic cardiomyopathy</li> <li>alcoholic gastritis</li> <li>alcoholic liver disease</li> <li>chronic pancreatitis (alcohol induced)</li> <li>foetal alcohol syndrome</li> <li>Wernicke-Korsakoff syndrome</li> </ul>	<ul> <li>malignant neoplasm of the gastrointestinal system</li> <li>malignant neoplasm of the breast</li> <li>epilepsy</li> <li>hypertensive diseases</li> <li>cardiac arrhythmias</li> <li>haemorrhagic stroke</li> <li>ischaemic stroke</li> <li>chronic pancreatitis</li> <li>psoriasis</li> <li>low birth weight</li> <li>spontaneous abortion</li> <li>diabetes</li> <li>ischaemic heart disease</li> <li>depressive disorder</li> <li>anxiety disorders</li> </ul>

Figure 16.3 Adult smoking prevalence in Great Britain, 1974-2011, by gender, adults aged over 16



Source ONS General Lifestyle Survey 2011.

# Scale of the problem – tobacco

Smoking is one of the largest causes of preventable mortality and morbidity, both worldwide and in the UK. Every year smoking (and secondhand smoke) kills 6 million people around the world, <sup>29,30</sup> including 79,000 people in England.<sup>31</sup> Quitting smoking reduces health risks to near normal levels within 10 years of stopping.<sup>32,33</sup>

In 2005, the World Health Organization (WHO) Framework Convention on Tobacco Control outlined a set of demand and supply reduction strategies that included both population and individual measures – price increases, tobacco promotion bans, bans on smoking in public places and workplaces, mass media education and information about smoking, treatment for smokers and widespread surveillance and monitoring.

In the UK, major progress has been made over the last half century. Smoking prevalence in the UK has now fallen below 20% for the first time in 80 years<sup>5</sup> (see Figure 16.3). These reductions continue to accrue,<sup>5</sup> including reduced smoking by children and teenagers.<sup>3,4</sup>

However, as smoking prevalence has decreased, a large socio-economic gap has emerged, with smoking now twice as prevalent in economically less advantaged communities<sup>35</sup> and at even higher levels among other disadvantaged groups (e.g. prison inmates).<sup>11,36</sup> Smoking is now the key driver of health inequalities in England.<sup>37</sup> A key development over the last 20 years has been the recognition that smoking is an addiction, driven by nicotine.\* This has prompted the development of effective treatments for smoking, utilising nicotine replacement therapy (NRT), varenicline, behavioural support and other interventions to increase successful quitting.<sup>38</sup> Health professionals can increase the uptake of

these evidence-based interventions. Disappointingly, however, identification, advice and signposting to effective support for smokers by health professionals are still not routine.<sup>39,40</sup>

# Scale of the problem – illicit and non-prescribed drugs, with a focus on heroin/opiates

Illicit drugs are used by approximately a quarter of a billion people worldwide. According to the 2014 World Drug Report from the United Nations Office on Drugs and Crime, an estimated 162–324 million people used an illicit drug at least once in 2012 (5.2% of the global population aged 15–64),<sup>41</sup> including 125–227 million using cannabis, 14–21 million using cocaine and 13–20 million using opiates. Approximately 10% of this total population used a drug by injection (mostly heroin but also cocaine). The United Nations estimates that 27 million people have a drug problem.

According to the 2010 Global Burden of Disease Study, dependence on illicit drugs accounts for 20 million DALYs (0.8% of global all-cause DALYs), with heroin/opiate dependence prominent at 9.2 million DALYs.<sup>42</sup> Injecting drug use is also a risk factor for HIV (2.1 million DALYs) and hepatitis C (0.5 million DALYs). The UK is among the countries with the highest rate of burden (alongside the US and Russia).

Of the illicit drugs used in the UK, heroin is notable for being acutely hazardous and aggressively addictive, with an estimated quarter of a million heroin/opiate dependents.<sup>43</sup> After rising relentlessly for a quarter of a century, the population of illicit opiate users in England has been falling modestly in recent years (see Table 16.3).

Table 16.3 Estimated number of opiate users and rate (thousands) population, England (2004-2012)

Year	Number of opiate users (95% CI)	Opiate rate per 1,000 population (95% CI)
2004/05	279,753 (292,941–292,941)	8.53 (8.48–8.88)
2005/06	286,566 (281,668–299,394)	8.60 (8.46–8.99)
2006/07	273,123 (268,530–283,560)	8.11 (7.98–8.42)
2008/09	262,428 (258,782–268,517)	7.69 (7.58–7.90)
2009/10	264,072 (260,023–271,048)	7.70 (7.58–7.90)
2010/11	261,792 (259,260–269,025)	7.59 (7.52–7.80)
2011/12	256,163 (253,751–263,501)	7.32 ( <i>7.25–7.53</i> )

<sup>\*</sup> For more information see https://www.rcplondon.ac.uk/publications/ nicotine-addiction-britain

# Box 16.3 Novel Psychoactive Substances also known as 'Legal Highs'

Over the last 10 years, novel psychoactive substances (NPS) have flooded the UK market, advertised in head shops and over the internet as 'safer' and 'legal' alternatives to illicit drugs. In reality, information on their effects is minimal or inaccurate, and what we are currently seeing is that they can be just as harmful and addictive as illegal drugs like cocaine, ecstasy and ketamine. The regular development of further NPS, combined with the ability of the Internet to spread information quickly, presents a number of challenges for public health around the world. In 2013, more than one new substance was reported every week.

The products are just a click away from our homes and are therefore available to everyone, including young people, who are among the most at risk. Convenient labelling of NPS maintains that they are 'not for human consumption', creating a loophole which can sometimes allow them to be distributed cheaply and remain legal and easy to obtain.

NPS have enjoyed a boom in popularity in particular because of the inability of standard drug tests to identify them. While users view this as an advantage, without knowledge of their pharmacological/toxicological profile their use is considered dangerously experimental.

Many NPS are research chemicals, sometimes even discarded products from drug research. They are produced mainly in Asian countries and usually on a large scale. Overall, NPS belong to a range of categories, including:

- latest generation phenethylamines/MDMA-like drugs, such as 'fly' drugs, NBOMe derivatives, DMAA and a range of indanes
- scannabimimetics ('spice', 'K2' drugs)
- synthetic cathinones ('meow meow', 'bath salts' and others)
- latest generation tryptamine derivatives such as 5-Meo-DALT, AMT, etc
- GHB-like drugs
- PCP-like drugs, such as methoxetamine, 3-MeO-PCP, etc
- piperazines, e.g. BZP
- herbs/plants, such as Salvia divinorum, Mytragina speciosa/kratom
- medicinal products, including a range of opiates/ opioids, gabapentinoids, novel benzodiazepines/ sedatives (e.g. phenazepam or 'Zannie'), stimulants (e.g. ethylphenidate) and antiparkinsonians/ anticholinergics (e.g. orphenadrine, tropicamide)
- performance- and image-enhancing drugs: superstrength caffeine tablets, cognitive enhancers (e.g. piracetam).

This text was kindly supplied by Professor Fabrizio Schifano, CRI Consultant Psychiatrist and Chair in Clinical Pharmacology/Therapeutics at the University of Hertfordshire In England during 2012, approximately 155,000 patients received treatment for heroin/opiate addiction,<sup>44</sup> with patients aged over 40 making up 34% of this total.

Non-medical use of and addiction to prescription opioid medication is a cause for concern, particularly in the US,<sup>45</sup> Canada<sup>46,47</sup> and Australia.<sup>48</sup> To date there has not been an equivalent visible increase in non-medical use of these medications in the UK. GPs will continue to have a vital role in the appropriate prescribing and clinical monitoring of patients' response to painkiller medications and onward referral to specialist services.

Health complications from the use of illicit drugs include HIV/ AIDS, hepatitis C and hepatitis B infection – primarily from sharing used needles and syringes, but also through sexual contact. Widely available opiate substitution treatments (OST) and needle and syringe exchange schemes have been key evidence-based components of the UK's effective healthcare response. 49,50,17,42 However, hepatitis C infection has become widespread, affecting more than 50% of injectors.

Heroin/opiates warrant special attention because, even though they are less widely used, they are significantly burdensome to global health and are particularly implicated in drug-related deaths (hypoxia following overdose being the most common cause). The focus on helping patients and their families to recognise and reduce behaviours that increase the risk of opiate overdose, and on how to manage overdose emergencies, is an essential component of competent clinical care.

A very high prevalence of heroin use exists in the prison population. In England, more than a quarter of all those detained in prisons (on remand or sentenced) have been found to have a history of heroin problems. <sup>51,52,9,53</sup> There is also a high prevalence of problems with alcohol and other drugs, and mental health co-morbidity. <sup>54</sup> The period in prison can be an opportunity to address untreated physical and mental health problems, <sup>55,56</sup> especially following the transfer of responsibility for prison healthcare to the NHS.

Heroin (and opiates generally) contribute disproportionately to drug overdose deaths (they are responsible for more than 50% of them). Release from prison is a time of marked excess mortality for those with a history of heroin use. <sup>57,58</sup> Other intense clusterings of deaths have been reported when users leave hospital <sup>59,60</sup> or drug-free rehabilitation. <sup>61</sup>

### Scale of the problem – benzodiazepines

Estimates of the prevalence of normal-dose users, high-dose users and misusers of benzodiazepines vary widely.<sup>62,63</sup> Many normal-dose users are maintained for years on therapeutic doses and encounter few problems until they try to withdraw. Prescriptions dispensed from community pharmacies across England can be examined over time<sup>64</sup> (see figure 16.4).

A large survey of benzodiazepine use across Europe interviewed representative samples in France, Germany, Italy and the UK<sup>65</sup> equating to over 200 million people. Sleeping

tablets were being taken by 1.6% of the population of the UK. The rate of anxiolytic use in the UK was 0.6%. Two-thirds of subjects had been taking benzodiazepines continuously for over a year.

Many studies have looked at benzodiazepine use in the elderly.<sup>66</sup> They have found usage to be greater, of longer duration and associated with more problems (such as falls and fractures) than usage in younger adults.<sup>67</sup>

Sedation is the most common subjective effect of benzodiazepines, despite the onset of some tolerance. Objective effects such as poor co-ordination are related to dose, compound and individual sensitivity. Acute and short-term administration of benzodiazepines clearly impairs higher brain functions such as learning and memory. Alcohol and other drug use magnifies these effects. In a meta-analysis, improvement was seen in all areas of cognitive function up to 6 months after withdrawal. <sup>68,69</sup> In addition, sedative drugs increase the likelihood of accidents and injuries. Paradoxical excitement can also occur.

Cognitive, psychomotor and practical impairments often become greater with longer-term use of benzodiazepines. Severe cognitive decline may ensue and may be misdiagnosed as a dementing process.<sup>19</sup>

A withdrawal syndrome occurs particularly with high-dosage and long-term use, but its severity is less closely dose related. Severe withdrawal symptoms can occur with sudden cessation, and also sometimes with slow withdrawal over several months or even years. The most characteristic symptoms are hypersensitivity to light, sound and touch. Occasionally fits or paranoid or confusional psychosis may occur.

# The importance of addressing addictions

A cultural change is required within the NHS and social care organisations to combat stigma and discrimination against people with addiction problems, and to ensure equity of care and delivery of effective interventions to address addiction problems and related health problems.

Active participation of all healthcare staff is crucial to discharge responsibilities of duty of care – both duty to detect and duty to act.

### Addressing addictions – alcohol

Effective public health measures to reduce harmful drinking need to include measures to reduce the affordability and availability of alcohol, thereby reducing alcohol-related harm at a population level.<sup>72</sup>

All NHS staff need to be competent to deliver appropriate care for people who consume alcohol in a hazardous or harmful way.<sup>4</sup> This should include alcohol screening and brief advice, with referral to specialist alcohol services for patients

14,000,000 12,000,000 Z-drugs" 10,000,000 all Hypnotics 8,000,000 all Anxiolytics all Benzodiazepines 6,000,000 Hypnotic Benzodiazepines 4,000,000 Anxiolytic Benzodiazepines 2,000,000 2004 2005 2006 2007 2008 2009 2010 2011 2012 2013

Figure 16.4 Prescription items dispensed in the community, England 2004 to 2013

Source Prescription Cost Analysis – HSCIC, Prescribing and Primary Care Services

with alcohol dependence or those who do not respond to brief interventions.

Only a small minority of people with alcohol dependence currently access specialist alcohol treatment, even though their condition requires more specialist care. Special integrated care will be required for high-morbidity complex cases. In South East London this has been supported by the development of a shared NHS alcohol strategy between the acute and mental health trusts, and academic and community stakeholders described in Box 16.4. This has included a fast track admissions pathway for patients with complex alcohol problems between A&E and the specialist inpatient addictions unit (see Box 16.2) and assertive outreach services for frequent alcohol related hospital attenders. The benefits of a shared local strategy include developing an integrated approach to meeting the needs of patients with complex alcohol related problems who are difficult to engage in conventional alcohol services.

# Addressing addictions – tobacco

All front-line health professionals need to give very brief advice. The burden on busy health professionals is therefore minimal. They need only raise the issue of smoking, remind smokers that support increases the success of quit attempts, and refer smokers to receive that support.<sup>74</sup>

An effective health service is health-promoting. Secondary and mental health NHS services are becoming completely smoke-free.<sup>75</sup> Accessible support for all smokers should be advertised before smokers come in as patients, and must then be offered throughout patients' stays and linked to community stop smoking services on discharge. Staff who smoke should be helped to quit and should be supported in doing this. (For an example of tackling smoking in a NHS mental health trust see Box 16.5.)

Levels of smoking among those with mental health problems are at least double those of smokers without such problems, <sup>76</sup> and have not tracked decreases in smoking in the general population. <sup>77</sup> Failure to monitor the physical health of people with mental health disorders contributes to this situation. Contrary to folklore, stopping smoking appears to be associated with improvements in mental health. <sup>7</sup>

Smoking is an addiction: this has triggered harm reduction strategies.<sup>78</sup> Continued smoking is largely driven by dependence on nicotine, whereas the damage done is due to other components of smoke. In 2013, NICE published ground-breaking guidance on tobacco harm reduction,<sup>40</sup> which now needs implementation.

# Box 16.4 The King's Health Partners Alcohol Strategy as an example of a local strategic approach to the care of patients with alcohol problems in contact with acute and mental health services

Good Health is a shared alcohol strategy developed across the King's Health Partners Academic Health Science Centre (see http://www.khpalcoholstrategy. org). Developed by bringing together a wide range of key stakeholders across the acute and mental health trusts, academia, public health and the local community, the strategy aims to reduce alcohol related harm in the population served by King's Health Partners. It is supported by funding from Guy's and St Thomas' Charity.

The strategy includes several components to improve care for patients who misuse alcohol. It provides training for front-line clinical staff in acute and mental health care to identify, provide brief advice, and where appropriate refer patients with alcohol problems for more specialist help is a key component of the strategy.

It includes development of 7 days per week multidisciplinary Alcohol Care Teams to provide improved care and support for patients with alcohol problems across acute and mental health care, whilst they are in hospital, are being developed.

More assertive outreach interventions to better meet the needs of frequent alcohol related hospital attenders with complex needs are being developed and evaluated in partnership with King's College London. Improved methods of data linkage of hospital information systems are being developed to identify, intervene and monitor alcohol related admissions.

An alcohol occupational health strategy is being developed to improve the health of the King's Health Partners workforce, including 35,000 staff and 25,000 students.

Implementation of the strategy will be evaluated through funding from the NIHR South London Collaboration in Leadership in Health Research and Care (CLAHRC) and other research grants, and will be disseminated to the wider health economy in South London through the Health Innovation Network (Academic Health Science Network).

# Addressing addictions – illicit and non-prescribed drugs, with a focus on heroin/opiates

For many people, addiction to opiates is a persistent and relapsing disorder, and only a minority successfully achieve lasting recovery following a single episode of treatment. In the US, studies have suggested that three to four episodes of treatment are the norm before stable remission is achieved.<sup>79</sup>

Patients with heroin dependence need access to effective care. Co-morbid physical health problems are often overlooked, despite known elevated rates of cardiovascular and renal disease and diabetes among these populations, 80 as well as high prevalence of tobacco smoking. 81,82

Older patients with heroin/opioid dependence are an increasingly common population. Services need to link mental and physical healthcare.

Front-line healthcare professionals are vital to detection, intervention and onward referral for people with hazardous and harmful substance use. A new, single-page version of the Alcohol, Smoking and Substance Involvement Screening Test (ASSIST-Lite) can be completed in less than 2 minutes<sup>83</sup> (see Box 16.6).

For specialist services, the Addiction Dimensions for Assessment and Personalised Treatment (ADAPT)<sup>84</sup> enables clinicians to tailor treatment by assessing and monitoring changes in the severity and complexity of a patient's health and social problems and their individual strengths.

# Box 16.5 The SLaM Addictions Clinical Academic Group drives an ambitious strategy to address high levels of smoking among patients and staff at the local NHS mental health trust

People with serious mental illnesses die prematurely and have significantly higher medical co-morbidity compared with the general population. High rates of smoking cause much of this excess morbidity and mortality. The prevalence of daily smoking among people with major depression, bipolar disorder and schizophrenia is 57%, 66% and 74% respectively. People with a mental illness are likely to be heavier smokers and more nicotine dependent than smokers in the general population.

Extraordinarily high levels of smoking exist among patients of addiction services (more than 80%). However, there are also high levels of willingness (around 40%) among such patients to tackle their smoking dependence. There are high levels of smoking among staff working in the addictions field (at 45%, more than twice the rate of the general public).

The SLaM (South London and Maudsley NHS Foundation Trust) Addictions Clinical Academic Group is leading a trust-wide response to this health inequality and is implementing a three-year plan with three distinct elements:

- 1. Preparing to be smoke-free from October 2014
- Monitoring and sustaining a smoke-free environment and establishing a durable smoke-free culture across the whole organisation organization including electronic systems for reporting and referring all smokers for tobacco dependence treatment
- 3. Identifying groups who are treatment resistant and developing and testing novel treatments to enhance their previously unsuccessful quit attempts

### Actions include:

- 1. Setting up and leading a trust-wide committee to oversee the smoke and tobacco dependence treatment policy implementation across four hospital sites, ensuring trust-wide delivery
- Supporting each hospital site in forming a 'site committee' to help it become smoke-free ready, thereby enabling a tailored response to the policy
- 3. Rolling out a trust-wide training initiative to support clinical staff to acquire skills and competencies in pharmacological and behavioural treatment of tobacco dependence, including guidance on the use of the range of nicotine replacements, e-cigarettes, plus bespoke training for other staff groups e.g. porters, gardeners, domestic staff
- 4. Reviewing all sites to remove smoking shelters and associated paraphernalia and introducing new smoke-free signage
- 5. Production and wide distribution of Frequently Asked Questions' and regular briefings
- 6. Service user and staff engagement, consulting on 'how' rather than 'whether' to go smoke-free
- 7. Developing and strengthening new electronic referral systems and a comprehensive clinical pathway for tobacco dependence for patients and staff across the whole Trust
- 8. Developing mechanisms for monitoring levels of smoking among patients locally and connecting with national databases
- 9. Allocating each site a named specialist smokefree adviser to support both patients and staff in achieving and maintaining their newly acquired smoke-free status.

# **Box 16.6 Example ASSIST-Lite questions**

The following questions ask a patient about their use of psychoactive substances in the past 3 months. All questions are answered yes/no, with additional questions asked for each substance used.

- 1. Did you smoke a cigarette containing tobacco?
- 1a. Did you usually smoke more than 10 cigarettes each day?
- 1b. Did you usually smoke within 30 minutes of waking?
- 2. Did you have a drink containing alcohol?
- 2a. On any occasion, did you drink more than four standard drinks of alcohol?
- 2b. Have you tried and failed to control, cut down or stop drinking?
- 2c. Has anyone expressed concern about your drinking?
- 3. Did you use cannabis?
- 3a. Have you had a strong desire or urge to use cannabis at least once a week or more often?
- 3b. Has anyone expressed concern about your use of cannabis?
- 4. Did you use an amphetamine-type stimulant, or cocaine, or a stimulant medication not as prescribed?
- 4a. Did you use a stimulant at least once each week or more often?
- 4b. Has anyone expressed concern about your use of a stimulant?
- 5. Did you use a sedative or sleeping medication not as prescribed?
- 5a. Have you had a strong desire or urge to use a sedative or sleeping medication at least once a week or more often?
- 5b. Has anyone expressed concern about your use of a sedative or sleeping medication?
- 6. Did you use a street opioid (e.g. heroin) or an opioid-containing medication not as prescribed?
- 6a. Have you tried and failed to control, cut down or stop using an opioid?
- 6b. Has anyone expressed concern about your use of an opioid?

Supplementary material can be found by online paper 'Ultra-rapid screening for substance-use disorders: the Alcohol, Smoking and Substance Involvement Screening Test (ASSIST-Lite).' (Ali R, Meena S, Eastwood B, Richards I, Marsden J., 2013 http://www.ncbi.nlm.nih.gov/pubmed/23561823)

# Addressing addictions – benzodiazepines

Much benzodiazepine prescribing is for unlicensed or unspecified indications ('off label') or exceeds the licensed duration of use (typically 4 weeks as an anxiolytic or 2 weeks as a hypnotic).<sup>85</sup> Specialist drug treatment services have been experiencing a rise in the number of cases involving sedatives and tranquillisers. This raises legal issues about breaches of the duty of care, laying prescribers open to actions for negligence and personal injury.<sup>86</sup>

The various issues relating to use of benzodiazepines are not as clear cut as the apparent public consensus suggests. More frequently than not, prescribed doses are not considered to be excessive. In addition, despite the received wisdom, some patients find these medicines helpful (without an intolerable burden of adverse effects) and claim that their efficacy does not diminish over time.

Official recommendations concerning the use of these medicines are widely ignored.<sup>†</sup> There is concern that some patients may be denied appropriate treatment because of undue fears. Treatment guidelines must be applicable in the 'real world' of clinical practice.<sup>87</sup>

The issues of abuse and dependence will continue to raise concerns. Scheduling is in place but major loopholes exist on the Internet, to which access is effectively unlimited.<sup>88</sup> It will be a Sisyphean task to control such self-medication.

# Improving planning and provision

All NHS staff need to screen, deliver brief interventions and, when necessary, make appropriate referrals to specialist services. There is a duty of care, including a duty to act. Failure to treat patients with addictions has a detrimental impact on health and mortality, and incurs considerable costs to the NHS and wider society.

There are clear public health and economic benefits from the early detection of clinically significant, low/moderate-severity substance problems. People at this end of the problem spectrum are not seen within specialist addiction treatment services, but they do have regular contact with their primary care practice and the family doctor is the natural first point of contact. The primary care setting is therefore well positioned for screening and offers of help to people with low/moderate-severity problems. Brief interventions for reducing excessive alcohol use and helping patients quit smoking can be delivered effectively in the primary care setting.<sup>89–91</sup>

Specialist treatment services for people with more severe addiction problems also need to be commissioned,

<sup>†</sup> See Lader, M. 'Benzodiazepines revisited – will we ever learn?' Addiction, 2011; 106: 2086-210.

resourced and provided based on the prevailing need in local populations. NICE guidance sets out recommended effective treatment interventions at the specialist as well as the generic level – technology appraisals, clinical guidelines and quality standards. <sup>92–94</sup> As yet, implementation is patchy in all addiction areas.

# Improving planning and provision – alcohol

Public health measures directed at the whole population have a strong evidence base and are recommended by both NICE and WHO.<sup>26,95</sup> Effective measures include reducing population level alcohol consumption through taxation<sup>72</sup> and raising the minimum unit price at which alcohol can be sold.<sup>96</sup> The latter is a more targeted measure towards heavier and underage drinkers. Reducing affordability reduces harmful drinking and alcohol-attributable diseases. Restricting availability through reduced hours of sale and reduced density of outlets is also evidence based and effective.<sup>72</sup> Public or school education campaigns on alcohol are ineffective unless carried out in conjunction with effective alcohol counter-measures.

People who drink in a hazardous or harmful way, in which their drinking is potentially or actually causing health harm, can benefit from opportunistic screening and simple, brief interventions provided by general health and social care professionals. 95 The benefits include reduced alcohol consumption, improved health and reduced NHS service use. Simple, brief interventions are both effective and cost-effective. 95 However, they are rarely implemented in typical clinical practice. This implementation gap relates to negative attitudes, lack of training and competing priorities for front-line staff. 97 Policymakers need to provide effective training, incentives and support to encourage wide-scale implementation.

Alcohol dependence is estimated to affect 1.6 million adults in England.<sup>4,93</sup> NICE has identified interventions for alcohol dependence which are effective when delivered in evidence-based care pathways. However, only 109,683 (7%) of alcohol-dependent adults were in contact with structured specialist treatment interventions in 2011/12.<sup>98</sup> This gap partly relates to the failure to identify alcohol dependence in primary and secondary care, and the inadequate capacity of specialist treatment services.<sup>4,93</sup> There is also considerable variation in the level of access to treatment across England, ranging from 8% in the highest-performing region to less than 1% in the lowest.<sup>99</sup>

Some people with alcohol dependence are particularly hard to engage in alcohol treatment by virtue of a variety of factors, including social disadvantage and exclusion, lack of awareness of the health harms of alcohol and fear of social stigma. This group often experiences multiple mental, physical and social consequences and, as a result, incurs considerable costs across the NHS and social care and criminal justice services. These are additional and currently missed opportunities to engage. Care for this population needs to be properly co-ordinated within an integrated care pathway.<sup>4</sup>

### Improving planning and provision – tobacco

Treatments of proven efficacy can increase smokers' chances of stopping successfully. The most effective treatment is a combination of pharmacological and behavioural support, which increases the chances of stopping successfully fourfold (compared with no support). Such treatment is available in community stop smoking services. 102,103

Brief advice from health professionals can trigger successful quit attempts.<sup>104</sup> Behavioural support includes strategies to manage cravings and withdrawal symptoms, <sup>105,107</sup> and guidance on the use of pharmacological treatments. Group support is more effective than individual support, with specialist advisers being more effective than those delivering cessation support alongside other clinical duties.<sup>108</sup> Behavioural support can also be delivered via telephone,<sup>108</sup> text messaging or the Internet.

Pharmacological treatments include nicotine replacement therapy (NRT), bupropion and varenicline. NRT is now available in several different forms: gum, patch, lozenge, sublingual tablet, nasal spray, inhalator, buccal pouch, mouth spray and dissolvable strips. There is no evidence favouring one form, apart from higher doses being more effective.<sup>104</sup>

Smokers who cannot stop abruptly need help to cut down in the interim, with encouragement to switch to alternative forms of nicotine. Electronic cigarettes (battery-powered devices that deliver nicotine via inhaled vapour) were introduced in 2004 and have increased rapidly in popularity. Only 8% of current smokers had tried e-cigarettes in 2010,<sup>109</sup> rising to 52% by 2014.<sup>110</sup> E-cigarettes contain no tobacco and are not burnt, and nicotine itself is much safer than tobacco smoking.<sup>111</sup>

E-cigarettes help more smokers to quit<sup>112,113</sup> and increase the success of quit attempts.<sup>114</sup> A small pilot that tested e-cigarettes with people with serious mental illness found reduction/cessation of cigarette smoking<sup>115</sup> and also that e-cigarettes appeared to enable the quitting of tobacco, even in those unwilling to stop.<sup>116</sup>

Some concerns have been raised about e-cigarettes including their potential attractiveness to young never-smokers, the recent entry of the tobacco industry to the e-cigarette market and, at the time of writing, marketing and product standards had not been introduced. Monitoring and surveillance are warranted so as to detect, at an early stage, any evidence of significant unintended consequences and ensure that their implications for public health are guided by the evidence base. However, the approach holds real potential, if the greater 'grip' on the target population can be utilised to effect robust quitting of tobacco-smoking.

Outside the health service, other population-led tobacco control strategies need attention. Priorities include further hard-hitting mass-media campaigns,<sup>117</sup> implementation of standardised packaging which has recently been associated with a dramatic drop in daily smoking prevalence in Australia,<sup>118,119</sup> a licensing system for retail outlets selling

tobacco and extending smoke-free places (e.g. banning smoking in cars carrying children).

# Improving planning and provision – illicit and non-prescribed drugs, with a focus on heroin/opiates

Heroin/opiate addiction is notable for several evidence-based interventions that exist at public health and individual health levels, which can produce major health benefits.<sup>17,50</sup>

Opiate Substitution Treatment (OST) has been extensively studied and reviewed by Cochrane<sup>120–123</sup> and NICE<sup>92,93,12</sup>4 and comprises supervised daily methadone (a long-acting oral opioid) or sublingual buprenorphine, moving to unsupervised dosing when good adherence and drug-free behaviour are achieved.<sup>125,126</sup> OST (and other interventions) are subject to routine outcome monitoring in England: the National Drug Treatment Monitoring System covers all publicly funded services, and records clinical outcomes<sup>127,128</sup> and benchmarks performance for all services for local commissioning.

However, problems of attrition remain, and treatment requires regular review and adjustment (particularly if illicit use or injecting persist).<sup>129</sup> A more recovery-orientated approach incorporating OST has been described.<sup>125</sup> In this approach, interventions are tailored to each patient's needs by phasing or sequencing appropriate care and ensuring access to other services as required.

While methadone and buprenorphine are the front-line medication-assisted treatments for opioid addiction, a small sub-set of entrenched heroin addicts exists who appear treatment resistant and for whom intensive treatment with supervised heroin maintenance has shown good benefits<sup>130–133</sup> and is a necessary second-line treatment.

The opposite approach (i.e. using opioid antagonists/blockers) utilises naltrexone, which NICE has reviewed<sup>93,13</sup>4 and found to be cost-effective, but with extremely poor adherence. Despite highly efficient opiate blockade, poor adherence limits the benefit obtained.

A separate, important component of public policy response involves needle and syringe exchange schemes, as reviewed by NICE.<sup>135</sup> The purpose of these is both individual health benefits (quitting the sharing of needles/syringes and avoiding infection with the HIV, hepatitis B or hepatitis C viruses) and public health benefits (reduced transmission of these infections).

Community-based mutual aid (e.g. Narcotics Anonymous) has an encouraging recent research evidence base: <sup>136</sup> NICE recommends that clinicians facilitate initial contact. <sup>137</sup> Drugfree residential rehabilitation has attracted criticism from Cochrane for a lack of randomised controlled trial-type evidence, but is important for those for whom OST is not appropriate, does not deliver benefits or is not acceptable. <sup>17</sup>

Hepatitis B vaccination is simple and effective, and yet is rarely provided. Vaccination through prison healthcare delivers

benefits.<sup>55,56,139</sup> Recent community-based studies identify much higher levels of vaccination with voucher incentive programmes.<sup>140,141</sup>

In hospital and ambulance settings, an injection of naloxone (an opioid antagonist) rapidly reverses opioid overdose, and is routinely used. Take-home emergency naloxone schemes provide a pre-supply of naloxone, plus training in overdose management to family members, non-medical potential first attenders (e.g. hostel staff) and friends (including peer drug users). National schemes now operate in Scotland<sup>142</sup> (see Box 16.7) and Wales, <sup>143</sup> and wider implementation is recommended by the Advisory Council on the Misuse of Drugs. <sup>144</sup>

# Improving planning and provision – benzodiazepines

Caution needs to be exercised with benzodiazepine prescribing and use. Two groups are at particular risk:<sup>145</sup> those using benzodiazepines for a long time for a chronic disorder (e.g. insomnia) who do not abuse their prescriptions;<sup>146</sup> and those who abuse their prescriptions or buy benzodiazepines illicitly – this is usually associated with other substance misuse (e.g. of opiates).<sup>147–149</sup>

Problems with benzodiazepines are being extrapolated to other psychotropic drugs, causing an increasing perception that all psychotropic drugs are 'addictive'. This imperils more valuable medications, such as antidepressants in the severely depressed.

A stepped-care approach to benzodiazepine discontinuation is recommended, beginning with advice from the GP and systematic tapering of the dose. These minimal interventions are often surprisingly cheap and effective. <sup>150,151</sup> Hospital-based discontinuation is used as a last resort. Substitution of a long-acting benzodiazepine such as diazepam is often used to facilitate withdrawal. Three major intervention approaches are effective – education, audit and feedback – and alerts are also key; <sup>152,153</sup> after this, tapering over weeks or even months should be instituted. Similar regimens are effective in the elderly. <sup>153</sup> Problems may be more challenging for the remaining severely dependent patients.

Clinical management in Northern Ireland utilises exemplary comprehensive advice to GPs on prescribing and withdrawing benzodiazepines and Z-drugs (see Box 16.8), including general advice, appropriate questionnaires and case reports. In general, patients' advocacy groups would prefer a national tranquilliser treatment agency to be set up, separate from the existing addiction treatment centres.

# Box 16.7 Pre-provision of emergency takehome naloxone to prevent opioid overdose deaths (Scotland)

Rates of drug-related deaths in Scotland are among the highest in Europe. The majority of these deaths is accidental, involve opioids, are witnessed and are therefore preventable. In 2011 the National Take-Home Naloxone (THN) Programme was launched and it was rolled out in 2011.

The THN programme is coordinated and monitored by an expert National Naloxone Advisory Group. The central programme supports:

- a Naloxone Coordinator and a Training and Support Officer;
- the development of information and training materials including www.naloxone.org.uk;
- reimbursement to NHS Boards for the THN kits issued in their area;
- in-depth monitoring and evaluation, including measuring progress against a baseline measure (by Information Services Division of NHS National Services Scotland).

In addition, a specific monitoring indicator has been established for the programme: a decrease in the number of opioid-related deaths, and opioid related deaths within 4 and 12 weeks of release from prison.

Increasing the reach and coverage of THN has been a Ministerial priority for Scotland's Alcohol and Drug Partnerships (ADPs). Each local health board area has a local naloxone coordinator and the Scottish Naloxone Network is a forum for local naloxone coordinators to share good practice, receive updates on current policy developments, and 'troubleshoot' relevant issues. 'Training for Trainers' is provided to local staff involved in provision; and a National Naloxone Peer Education Programme is provided for people who use (or formerly used) drugs and wish to become peer educators/trainers.

# **Training and supply**

Training in overdose management and emergency interim naloxone administration is delivered by a range of staff – nurses, pharmacists, voluntary sector workers and peer trainers, generally as a brief intervention (15-20 minutes) and occasionally in a group setting.

Training and supply takes place in the community and in all 15 prisons in Scotland.

Naloxone is a Prescription-Only Medicine, and a Patient Group Direction is used to provide naloxone – mainly by nurses working directly with people who use drugs, and in some areas by pharmacists (all after training).

Family members/carers can be supplied with THN (consent from the person 'at risk' of overdose must be provided). Services who may come in to contact with those at risk of overdose can be supplied with THN for use in an emergency, which is covered by the Lord Advocate's Guidelines.

Between April 2011 and March 2013 7,291 take-home naloxone kits were supplied as part of the scheme in the community and on release from prison.

For further detail, see the Service Evaluation of Scotland's Take-Home Naloxone Programme, May 2014 – http://www.scotland.gov.uk/Publications/2014/05/6648/0

# Box 16.8 The potential complexity of benzodiazepine withdrawal

'Prescribing and withdrawing benzodiazepines and "Z" drugs: A Resource for General Practice' (South Eastern Health and Social Care Trust, Northern Ireland)

The following bullet points are taken from an exemplary document ('Prescribing and withdrawing benzodiazepines and "Z" drugs: A Resource for General Practice', South Eastern Health and Social Care Trust, Northern Ireland, 2014) setting out the main principles for the prescribing of benzodiazepines and their subsequent withdrawal, as available in Northern Ireland. It contains much useful material including advice to patients on anxiety and insomnia, available resources including self-help groups, guidance on alternate treatments, questionnaires, case histories, etc.

- Initially choose a priority group, e.g. chronic users and/ or those on high doses
- Assess motivation to change patient/carer information leaflets
- Confirm diagnosis of dependence including urine screen
- Distinguish therapeutic dose dependence; prescribed high dose dependence; recreational high dose abuse
- Offer ADVICE (e.g. sleep hygiene), GUIDANCE (from trained professionals) and SUPPORT (counselling appointments)
- Switch to diazepam reduce in 2-weekly steps of 2 to 2.5 mg/day – monitor with BDZ withdrawal symptom questionnaire, sleep and anxiety diaries
- It is better to reduce too slowly than too quickly
- Structured strategies minimal intervention, a longer consultation, non-drug methods, referral to benzodiazepine nurse or Community Addictions Team (CAT)
- Treat any symptoms of depression
- Encourage regular exercise in reducing anxiety and insomnia

This document can be recommended as a model for services elsewhere and its advice can be readily implemented elsewhere. It can be accessed at http://www.setrust.hscni.net/services/2733.htm.

A longer guidance document is also available from the Substance Misuse Management in General Practice website at http://www.smmgp.org.uk/download/guidance/guidance025.pdf.

Continual monitoring of the situation is essential. In England, Clinical Practice Research Datalink data should track the extent of benzodiazepine and Z-drug prescribing by GPs. The data could be augmented by national surveys of community pharmacists to establish patterns of dispensing these prescribed medications. Attention should be focused on elderly people, particularly those using these drugs continuously over long periods.<sup>153</sup>

A specific problem relates to the self-aggressive behaviour caused by benzodiazepines.<sup>154</sup> The effects of these drugs on driving and road safety are currently being addressed, although the practical problems involved are considerable.<sup>155</sup>

# Authors' suggestions for policy

Seven key operational and clinical challenges that apply right across the addictions/dependence field need to be addressed, plus seven that are substance specific.

## Operational and clinical challenges (general)

- Duty of care comprises a duty to detect and a consequent duty to act. The GP, primary and secondary healthcare teams are key to increasing identification and appropriate interventions. Failure to identify and failure to treat have serious short-term and long-term consequences for the patient, their family and society.
- Responsible commissioning needs to ensure the delivery of interventions which are compliant with NICE guidelines and individually tailored. Brief (and simple) interventions are appropriate when sufficient and should be universally applied, but referral pathways for fuller interventions are also essential when benefits are not achieved.
- One size does not fit all. Competent commissioning must ensure balanced provision of all components of the layered pyramid of healthcare provision (see Figure 1). This must include close connection and integration with the planning and provision of wider mental health care services. This could be achieved more effectively by bringing addictions commissioning back into healthcare commissioning.
- More specialist interventions (often more intensive and expensive) must be available to individuals who fail to benefit from first-line treatments. These are vital for severely affected individuals and those with co-existing health disorders. Increasing specialist addiction treatment for the in-need population would improve public as well as individual health and would reduce costs.
- Specialist centres are a crucial component of the pathway of care and must be incorporated into the competitive marketplace of service providers. They are essential to maintain training and research capacity, as well as to care for more hard-to-treat patients.
- The existing mechanisms of medical education need strengthening in order to improve knowledge, confidence and competence in this area for all practitioners. This needs to include better training of medical students, doctors and other healthcare staff in basic detection and

- intervention skills, as well as knowledge of when and how to refer patients for more specialised care.
- Greater strategic research and development (R&D) investment is needed across the addictions field, including in epidemiology and clinical trials to remain abreast of changing trends in substance misuse. Existing R&D commissioning mechanisms must proactively identify clinically influential and policy-relevant research trials to inform improvements in preventive and treatment responses.

## **Substance-specific challenges**

- Alcohol increasing the price of alcohol is the most costeffective and targeted public health intervention to reduce harmful drinking, and has been endorsed by both NICE and WHO. Setting a minimum unit price below which alcohol cannot be sold would have the greatest possible impact on reducing alcohol-related harm in England.
- Alcohol increasing the penetration of alcohol screening, brief interventions for hazardous and harmful drinkers and specialist treatment for people with alcohol dependence would have a major public health impact in reducing alcohol-related ill health and costs to society in England.
- Tobacco a fifth of the population still smokes, despite good progress in recent years. Particularly high prevalence persists in more disadvantaged groups. The job is therefore not complete: tackling smoking needs continued and enhanced attention.
- Tobacco a totally smoke-free health service is needed, with a joined-up pathway for treating smokers from pre-admission to support in the community following discharge. Existing population-level measures must be sustained. New measures such as standardised plain packaging can further reduce smoking prevalence.
- Drugs the treatment of opiate addiction requires attention to both medication and non-medication components of care. Both components require adjustment to obtain the optimal benefits. A system is required for periodic checks of the health benefits being obtained, with particular care and attention paid to periods of change, terminations of treatment and continuation of care over this high-risk period.
- Drugs training in first responder emergency management of an overdose should be provided to the patient, their family and other carers, as well as to non-medical and medical staff in all agencies in contact with heroin/ opiate misusers. This includes how to give an interim intramuscular injection of naloxone while awaiting an ambulance.
- Benzodiazepines more intensive support and specialist assessment is required for patients whose withdrawal from benzodiazepines proves problematic. This will often require referral for assessment and more specialist interventions. However, this specialist expertise is scarce and needs development, alongside arrangements for the commissioning of regional referral arrangements.

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# Chapter 17

# Ethnic inequalities, complexity and social exclusion in mental health

# **Chapter authors**

Kamaldeep Bhui<sup>1</sup>, Jean O'Hara<sup>2</sup>

- 1 Professor of Cultural Psychiatry and Epidemiology, Wolfson Institute of Preventive Medicine, Queen Mary University of London, East London NHS Foundation Trust
- 2 Consultant Psychiatrist and Clinical Director, Behavioural and Developmental Psychiatry Clinical Academic Group, King's Health Partners Academic Health Sciences Centre, South London and Maudsley NHS Foundation Trust

# Introduction

Previous research and equalities policies give significant attention to ethnic disparities in the incidence of severe mental illness, depression, suicide risk and experiences of adverse life events like discrimination, trauma (e.g. that experienced by asylum seekers and refugees), unfavourable social and housing conditions and unemployment.<sup>1–9</sup> This body of epidemiological and health services literature is reviewed elsewhere in this report (see Chapter 7 of this report, 'Life course: Adults' mental health'). Although much work is being undertaken to address pre-migration traumas and adversity as determinants of mental illness, health inequalities as a result of social conditions and the risks of illness after migration during periods of resettlement, and at contact with the NHS, are also important.<sup>8</sup>

In terms of care services, two previous policy reviews emphasised that people from diverse ethnic and cultural backgrounds (including migrants, asylum seekers and refugees) had inferior experiences and outcomes within mental health services. These included differing pathways to care, less use of primary care, difficulties in being diagnosed early, communications of distress that were not recognised by professionals, more hospital admissions (for black Caribbean and black African groups), less psychotherapy and more somatic interventions. Concerns centre around not receiving care or under-treatment of mental illness, as well as why more coercive treatments – for example, compulsory treatment – are more commonly used in some ethnic groups. 10,11,12 Greater contact with the criminal justice system and less use of primary care and public health have been consistently reported for African Caribbean patients.<sup>13</sup>

These inequalities of experience and outcome have been understood in terms of clinicians behaving differently and making decisions that are not fully cognisant of the cultural origins of the patient, let alone showing awareness of how professional cultures and systems of care impact on clinical decision-making. Calls for cultural competency training assume that there is poor understanding of how culture influences the expression of mental distress and how it might then impact on diagnosis and treatment. A response to these concerns was a national call during the Delivering Race Equality programme to teach cultural competency in order to improve staff skills in communication, interpretation, engagement, assessment and diagnosis.1 The literature on cultural competency is full of examples of good practice but contains very little evaluation of outcomes, particularly service user outcomes.<sup>14</sup> For patients whose first language is not English, additional help is needed in delivering care through appropriate and skilled translation and interpretation that can capture complex mental states and subjective experiences of distress so that these can be considered by a mental health specialist to inform clinical decision-making. 15,16 Trying to understand how to improve therapeutic communications for black and minority ethnic groups is a major challenge given that the diversity of interventions, outcomes and ethnic groups are all considered as belonging to one group with similar needs.12

# Cultural competency

Improving the assessment of explanatory models – that is, the personal and culturally grounded narratives of mental illness, what causes it and what may alleviate distress – is recommended, and new ways of assessing these models are now available. 17,18 One study in primary care showed variations in the recognition of common mental disorders in Punjabi South Asians by GPs, most of whom were themselves of South Asian origin.<sup>19</sup> Cultural variations in explanatory models, expectations of treatment and expressions of distress seemed to explain the different recognition rates. In one study, cultural similarity between the patient and the interviewer led to more reports of interpersonal violence and religious and spiritual causes, whereas dissimilarity led to more medicalised explanations, which were not influenced either by rapport with the clinician or social desirability.<sup>20</sup> At the same time, improving the mental health literacy of traditional and alternative carers sought out by people with psychological distress will help redirect them to appropriate care services.<sup>21</sup> Generally, improving community knowledge of mental illness and mental health and tackling stigma are all important to encourage early intervention. Previous work on encouraging improved pathways into and out of care, linking non-governmental organisation and NHS services, showed that this can yield positive benefits by enabling socially isolated and excluded groups to seek help and receive treatments, overcoming cultural taboos, restrictive gender roles and practical obstacles, and perhaps even reducing admissions among black Caribbean patients.<sup>22–25</sup>

Many interventions are being developed to improve outcomes for black and minority ethnic groups, including cognitive behavioural therapy (CBT) for psychosis. 26,27,28 There is also a culturally adapted approach to CBT for self-harming South Asian women.<sup>28</sup> Studies of complex community interventions have shown the benefit of fostering community-embedded, stepped-care arrangements in which local residents, businesses, churches and libraries all engage in a network that reduces stigma and serves as an access point to early assessment and intervention – in this instance interpersonal therapy – with ethnically matched therapists.<sup>29</sup> Cultural consultation, a process of gathering patient narratives and including them in decision-making, was pioneered in Canada and has been applied with promising preliminary findings. 30,31 This approach also empowers healthcare staff to reflect on their own practice in clinical settings rather than in the classroom, and brings into their deliberations the impact of their own cultural background, as well as the strains they experience in everyday practice and how these impact on the relationship with their patients.<sup>32</sup> A relatively understudied area is that of incorporating assessment of religious beliefs and spirituality into diagnosis and treatment, and understanding recovery.33

More studies are needed on interventions to reduce detentions, improve access to and take-up of treatment and encourage therapeutic alliance and appropriate referral, as well as on interventions to improve assessment and care planning that translate into improved outcomes. The subject of diagnosis of mental disorder across ethnic groups has been controversial, often fuelling concerns about under- and overdiagnosis. The fourth edition of the Diagnostic and Statistical Manual (DSM-4) in the US included a cultural formulation, which tried to take knowledge from social sciences (including anthropology) in order to encourage clinicians to consider the cultural identity of the patient, their explanatory models, their counter-transference (related to cultural factors in their own history and that of the patient), psychosocial adversity such as discrimination and poverty, and finally an overall diagnostic conclusion.34 DSM-5 has promoted the cultural interview, placing it in the main body of the manual and not in the appendix. This is the result of international field trials and looks promising, but awaits further evaluation.<sup>35</sup>

# Organisational cultural competency and commissioning

Good governance and organisational constraints can influence the outcomes and experiences of patients<sup>36</sup> and can enable staff to notice service users' narrative of suffering.<sup>37</sup> There are many substantial studies in the US that have examined mental health systems and how they interact with people from diverse cultural and ethnic groups – specifically migrants – and the way such services need to remove structural barriers to accessing effective interventions. For example, Siegel et al. set out the need for measuring cultural competency within three levels of organisational structure: administrative, provider network and individual caregiver.<sup>38</sup> Actions were recommended that included measures of benefit, needs assessment, information exchange, adaptation and development of services, human resources policies and key performance indicators.38 An organisational analysis of cultural competency from the US discovered the following elements: communication competencies (with the use of colloquialisms and accepted forms of address); staff in culturally acceptable roles; culturally framed trust-building (such as pairing young people with mentors); stigma reduction; creating a friendly milieu and offering services (e.g. serving culturally familiar foods and playing music popular with the culture); and peer, family and community involvement, including the use of peer counsellors and mentors, organising parenting weekends and linking clients with community services, including services for older people.

Although there is an evidence base, it is rare to see commissioning plans that include specific mention of meeting the particular needs of one ethnic/cultural group, or services to better meet the needs of culturally diverse populations as a whole. A recent report by Salway et al. focused on commissioning, with reviews across disease areas suggesting

that commissioners can reduce ethnic inequalities in poor health, but they need more confidence and commitment, and a means for monitoring progress and using evidence.<sup>39</sup> The report concluded that, rather than dealing with ethnic inequalities as a marginal agenda, commissioners must understand and address them as part of their core responsibilities, and exploit synergies with other key policy agendas such as quality, efficiency and health inequalities. There are many examples of good practice in clinical services, with excellent links between health, social care and the voluntary sector.<sup>40</sup> Yet these are not actively embraced in commissioning plans.

# **Emergency care**

There are also major concerns around emergency care pathways for patients with mental illness and their frequent contact with the police. An inquiry into policing and mental health chaired by Lord Adebowale concluded that the quality of emergency care was poor, inconsistent across NHS sites and that – given the police are dealing with so many people with mental illness, psychological distress or psychological vulnerabilities – more integrated emergency pathways were needed.41 It also suggested that NHS care needs to be consistent rather than dependent on local arrangements, and that the police and mental health professionals have complementary and clear roles and expectations. Although ethnicity was not the main feature of this report, given that some black and minority groups are especially likely to enter care through emergency pathways involving the police, or directly through crisis admissions, and forensic care sectors suggest a history of contact with the police, safer and more effective emergency care pathways would also protect and promote their mental health and help reduce inequalities in care experiences and outcomes. The data on forensic sector contact for black Caribbean people are long-standing, with little change for decades. Similarly, the data on excess compulsory treatment in hospital for some ethnic groups have not shifted.<sup>42</sup> New interventions and approaches are needed, as is more focused research to investigate to what extent this is due to the balance of inpatient and community resources or a lack of professional skills.

As regards contact with care services, previous work shows that some interventions have been tested to reduce coercion in care; for example, detentions and forensic care contact. 43,44 Studies of crisis plans to reduce admissions showed either no benefits<sup>45</sup> or a modest effect that suggested this may be a cost-effective intervention for black patients. 46 A study of people referred for Mental Health Act assessments in Oxford, London and Birmingham showed that black people were 1.35 times (OR, 95% CI: 1.137-1.602) more likely than white people to be detained; those living in Oxford and Birmingham were half as likely to be detained as those living in London; and then adjusting for city attenuated the association between being black and detention (OR=1.191, 95% CI: 0.996–1.124) which no longer reached significance. Clearly, living in a high-risk area is important in explaining the individual experience of detention. Yet the reality is

that people living in London who are black are more likely to experience detention. For them an adjustment in the statistical model does not offer any remedy, although the implication is that area level interventions may be helpful. The difference in beta coefficients for the ORs of 1.35 and 1.191 is 0.05442, which as a percentage of the original beta coefficient indicates that 41% of the excess is explained by the locality.

Such studies are important and help us piece together the complex influences that interact to produce poorer outcomes. There remain questions around whether adjustment for ethnicity in epidemiological studies is a reasonable approach to analysis, given that ethnicity and deprivation are closely associated and, some would argue, aspects of social exclusion. Material deprivation as a component of ethnicity is related to living in deprived areas with poorer public amenities, and is not entirely located to individual risks that are presented as ethnic group differences.<sup>47</sup> Similarly, care experiences are an interaction between the individual, their distress, family, professionals, social systems, the culture of care and care services. Studies and interventions need to embrace the complexity of care experiences and ethnicity as a process variable rather than a static category: areas/ contextual effects that interact with social support and poor mental health might mediate the effects of ethnicity. For example, studies in the US suggest that relationships exist between ethnic density and mental health, 48 while in the UK social capital is shown not to mediate the effects of ethnic density on health, although the characteristics of neighbourhoods continue to be expressed in contrasting ways by different ethnic groups. 49 This suggests that we need new levels and types of measurement of adversity, coping and distress that might further explain ethnic contrasts in experience and outcome.

# Public mental health

Although there remains some responsibility on care services to improve the assessment, diagnosis and treatment of mental illness, promising public health initiatives aim to identity early indicators of mental distress and offer preventive interventions that are cost-effective. 50,51 Some public health interventions might widen inequalities, so care is needed in designing and implementing interventions of this nature.<sup>52</sup> The limitations of ethnicity research that sees ethnicity as an embodied personalised risk – rather than as a dynamic interaction between individual vulnerability and adversity – have hindered more progress on preventive interventions; for example, ones that consider epigenetic risks. 53,54 Adopting a public health framework for understanding the aetiology and development of mental disorders does stress the prominence of social, psychological and environmental adversity as modifiable risks, yet more research is needed if this work is to help us understand the aetiology and higher risks of mental illness among some ethnic groups and offer preventive interventions for high-risk groups. For example, common psychotic symptoms are associated with urbanicity, discrimination and low ethnic density, are more common in

some immigrant groups, and are predictive of later psychotic disorder. <sup>55,56</sup> What can we do to the urban environment, and about schooling, discrimination and stigma, to combat these risks?

Studies in the US on ethnic disparities include theories about the fundamental causes of illness; these implicate social and material deprivation and adversity as drivers of illness.<sup>57,58</sup> One theory posits that people living in these conditions will get ill: their phenotypes relate to specific individual vulnerabilities and social contexts, and if all the causes of their illness are not tackled, the illness will persist.<sup>59</sup> For example, the relationship between socio-economic status and mortality has persisted despite changes in population socio-economic conditions and other risk factors that have been thought to explain diseases. The concept of syndemics, leading to co-morbidities, is also important as it breaks free of the mind-body dichotomy and ensures that fundamental causes are understood as being related to multiple diseases, not only a single disease. 60-63 The implication is that tackling multiple forms of disadvantage will reduce the risk of multiple disease outcomes and co-morbidities.

Similar processes might explain the propensity for detention, which is not only higher in areas in which there is more risk of psychosis, more deprivation and more adversity, but also reflects more fragmented and under-resourced services, more demand on services, and the fact that emergency care is offered at a crisis point rather than at an earlier stage of the care pathway. People with multiple adversities, poor social support and epigenetic risk profiles will be more susceptible within services that do not remedy the fundamental causes of mental distress in the community (public health services) and in care services (this is the remit of provider organisations). We can moderate social adversity, environmental risk factors and the capacity and delivery of services.

Although care services are focused on diagnosed disorders, a different and complementary approach is to ensure that public health interventions address the social determinants of mental illness and sub-threshold disorders. This includes the need for interventions throughout the life course (such as in schools, in homes and with parents) and measures to protect and promote safety and prevent gender violence and vulnerability to violence in general.<sup>64</sup> It is also crucial to maximise the health and wellbeing of the population and its resilience against adversity and trauma.<sup>65,66</sup>

There is a dilemma in that universal interventions tend not to be taken up if they are voluntary and based on educational interventions, risking a widening of inequalities in population indices of health and wellbeing. Therefore the requirements of socially excluded groups need to be accommodated within the public health outcomes framework and in policy and practice, just as targeted intervention in service settings is needed. A key opportunity in pursuing a public mental health approach is to link the risks of premature mortality and disability due to mental illness with risks related to other chronic diseases, as well as the social determinants of illness and biological vulnerability. Some of the groups that are at

Table 17.1 Groups at risk of developing mental health problems

Children and young people	Adults
■ Children with parents who have mental health or	■ People with mental illnesses
substance misuse problems	■ BME people
Children experiencing personal abuse or witnessing	■ Homeless people
domestic violence	Adults with a history of violence or abuse
Looked-after children	Adults who misuse alcohol or other substances
■ Children excluded from school	Offenders and ex-offenders
■ Teen parents	■ LGBT adults
■ Young offenders	200. 000.00
	■ Travellers, asylum seekers and refugees
<ul><li>Young lesbian, gay, bisexual and transgender (LGBT) people</li></ul>	Adults with a history of being looked after/adopted
	■ People with learning disabilities
Young black and minority ethnic (BME) people	■ Isolated older people
Children living in socio-economic disadvantage	= isolated older people

risk of policy and practice omission are listed in Table 17.1, each has specific and general adversities and protective factors, and each requires some tailoring of public health and healthcare interventions. All of these groups need specific policies within a co-ordinated overall framework for tackling inequalities within socially excluded groups.

We present a composite case study (see Box 17.1) that illustrates the way in which many risk factors interact in practice, such that a single diagnosis or single-service approach becomes unworkable. Although the case study relates to learning disability services, the experience of multiple and complex needs is found in many, if not all, specialist psychiatric services.

# Conclusion

An integrated approach that places mental health services within a public health framework is essential to offer people choice, avoid dependency and mitigate the long-term effects of adopting a sick role; at the same time, rapid and early assessment, diagnosis and intervention must be targeted at those showing consistent and persistent symptoms and patterns of presentation that are known to indicate the emergence of more severe mental illness. At the point of a new-onset mental illness, rapid intervention, protecting physical and emotional health, and minimising adverse effects and impacts on physical health (for example, obesity due to medication) are essential and should be undertaken irrespective of which service the patient is first diagnosed in. However, we must guard against the notion that early assessment and diagnosis are technically and professionally simple: we need a highly skilled and senior workforce that is confident and committed to making competent clinical decisions, and a legal and rights-based framework that is cognisant of the ethical use of resources to meet health needs and maximise choice. This mitigates the risk that diagnosis becomes the basis of inflexible care pathways, which might further restrict choice and compound social exclusion through stigma and discrimination.

At a time of economic downturn, one of the risks to mental health care is that it is seen only as a social intervention, targeting the environment. Important as that is, skilled assessment and psychiatric intervention – including social, psychological and pharmacological interventions – are also warranted, within a person-centred and shared decision-making process that offers choice, protection and access to effective treatment. Therefore, preventing inequality in the community, the health impacts of inequality on the vulnerable and inequalities of access, intervention and experience need a finely balanced health system with skilled and confident leaders, clinicians and commissioners.<sup>67</sup>

# Authors' suggestions for policy

- Skilled assessment requires a good understanding of how different systemic and individual factors can compound powerlessness and generate inequalities, for example by leading to a less adequate assessment and intervention if culture complicates communications. Language issues have an impact, and family and cultural factors are also influential, for example if there is an absence of parental protection, exposure to early adversity or changes in carers. Family influences and dependency require a more nuanced and systemic assessment.
- A focus on short-term interventions and outcomes is unlikely to be successful, and these should perhaps not be pursued until a wider understanding of consent, responsibilities and decision-making authority is obtained.
- There are intergenerational impacts and demands of parents and grandparents to consider, as well as impacts on children.
- Poverty, unemployment, powerlessness and linguistic distance all make it more difficult to engender trust and engage in the deep-seated process of treatment and recovery to which services aspire.
- Taking a systemic approach requires services to ensure that appropriate linguistic and assessment skills are available, and that cultural brokers or advisers are perceived as being

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neutral and helpful by the local community. Concerns about stigma also need tackling in a consistent manner, and cultural brokers and interpreters need to be trained and employed rather than being sought out on a patient-by-patient basis, which results in less certainty about skills and adherence to policies. These issues can be more systematically addressed if the staff and cultural group of interest make up a significant proportion of the local population. Otherwise a service has to be created to meet the needs of each patient; if this fails to happen they are less likely to receive effective interventions and to make the best use of them.

- While focusing on intersectional inequalities and complexity, it is easy to overlook the complementary place of personal and community resources in mental health promotion and the recovery of those with mental illness. This can play an important role in promoting self-efficacy and resilience, but should not be seen as justification for the removal of services, or for failing to meet the needs of people with mental disorders and psychological distress.
- Studies are needed of exclusion, co-morbidities and the manner in which environmental and individual characteristics interact to produce illness and disease states that limit function and participation. Fundamental causes of disease include social determinants that must be addressed, including child poverty, domestic violence, child abuse (including sexual and emotional abuse, violence and neglect), gender-based discrimination and other forms of violence. Early parenting interventions, including interventions by health visitors, are key, as is ensuring that people are skilled to protect and promote their own health and use health and social care more effectively.

# Box 17.1 Case study – Interaction of risk factors and diagnoses

### History

A Bangladeshi woman in her early 20s presents with a history of mild learning disabilities, with a suggestion of early cerebral palsy and/or co-morbid autism spectrum disorder. There are difficult and risky behaviours for her family to manage, and a possibility that psychotic experiences are driving her behavioural presentation.

Adult mental health services, accident and emergency services and primary care all know of this patient; she is on antipsychotic medications and has been referred to a specialist mental health service for people with learning disabilities. She attends with family members. There is a history of poor schooling opportunities in Bangladesh; she came to the UK following one parent for 'treatment'. There have been numerous family separations.

The patient was raised by her grandparents and her extended family. Little educational or developmental history can be obtained. Her family have invested considerable time and resources (personal and financial) in obtaining a cure for her learning and/or physical disabilities. There is a supportive extended family network in the UK but they are dispersed because of housing needs and a lack of housing for all in one area.

The family live in poverty and the men are out of work on a frequent basis, or working away from home or undertaking shift work, making it difficult for them to engage with services or contribute to decision-making. As a result, work with the family is conducted through the female members.

### **Assessment**

The assessment involves multiple home visits and attempts to see the patient alone, as different family groupings and members in different contexts work against a coherent story and diagnosis. Although a diagnosis is made and medication used, the family also seek out religious and complementary interventions; however, this information is not forthcoming and only emerges months into the treatment. A few months into treatment the patient misses several appointments, only to re-engage with services after returning from abroad.

### Commentary

This story is not uncommon and in many instances variations include the patient travelling abroad to get married and/or falling pregnant. It is unclear whether consensual sex is possible given that the patient's capacity to give consent is not assessable due to language and developmental difficulties.

Another theme is the request to assist with immigration matters, and then the belief that the patient should have children and remain at home in a child-caring role rather than pursue educational interventions. Concerns about the unborn child can lead to non-adherence with medications or other treatments, meaning that the mother loses even more control over her destiny, with other family members making more decisions for her.

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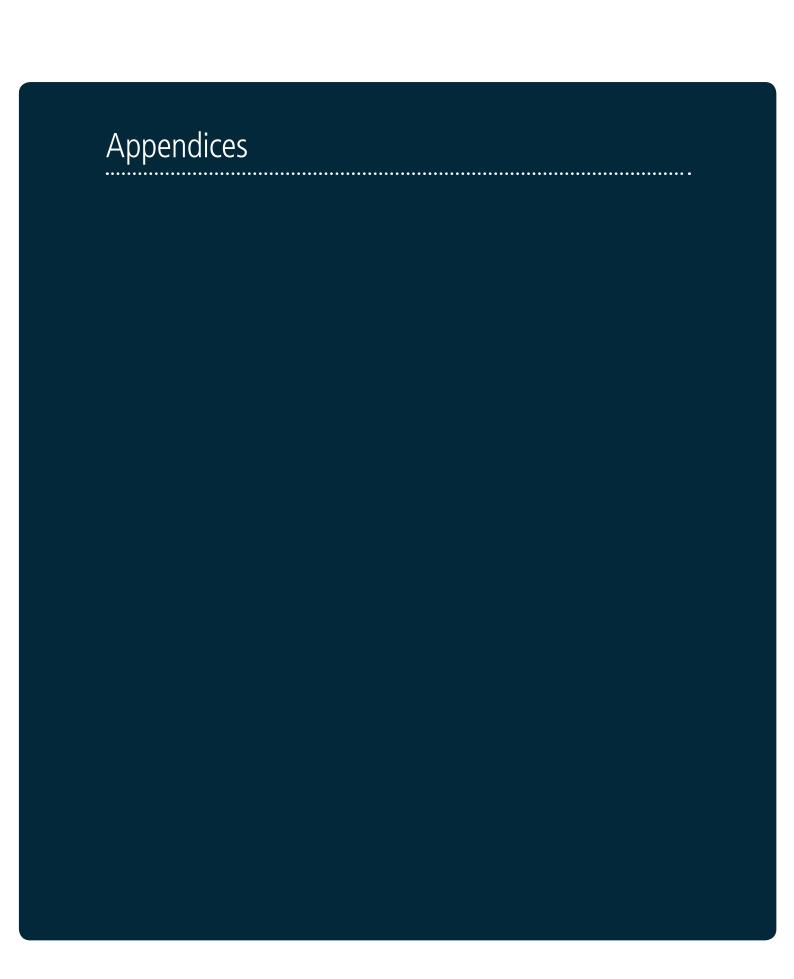
# Ethnic inequalities, complexity and social exclusion

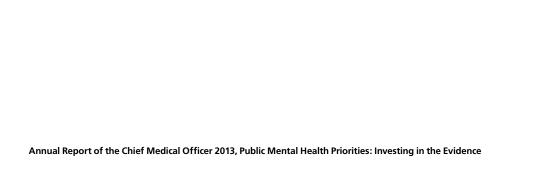
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# Appendix 1

# The definition and measurement of well-being and quality of life in mental health promotion and outcomes

**Author** Ann Bowling<sup>1</sup>

1 Professor of Health Sciences, University of Southampton

# Background

Promoting positive well-being and mental well-being is a current priority for health, social and community care commissioners, at both national and local government levels. The concept of well-being is one of the components of many definitions of quality of life (QoL), and is frequently used interchangeably with this concept. In 2010 the Prime Minister launched the National Well-being Programme to 'start measuring ... not just [economic growth] but ... how our lives are improving; not just by our standard of living, but by our quality of life'. There is an additional ongoing policy focus on improving the QoL of people with long-term. For policy outcomes to be relevant to people, outcome measures need to have relevance to people's lives, or to the wider areas affected by their conditions; have social as well as policy relevance; and be based on patients' reports. Patientreported outcome questionnaires are increasingly used in clinical trials and other evaluative and descriptive research. Information from these measures has a key role in policy making, as well as empowering patients and giving them a voice.

As long-term physical and mental health conditions can affect the whole of a person's life, there has long been a focus on self-reported QoL outcome measures, as well as indicators of well-being, one of its components. Many generic healthrelated and disease-specific QoL measures have been developed and tested. The former are appropriate for use with both general population samples and those with medical conditions, and the latter are appropriate for measuring disease-specific QoL outcomes in patient populations. Interest in measuring QoL outcomes in mental health, as opposed to specific elements such as social functioning, developed later than other clinical disciplines (e.g. rheumatology, cancers); most general components of QoL have long represented main areas of psychiatric intervention (e.g. psychological functioning impairment represents the main area of psychotherapeutic and psychopharmacological interventions; social functioning impairment is the main area of rehabilitation intervention) (Gigantesco and Guiliani 2011).

Both well-being and QoL have been conceptualised as largely subjective, with assessments based on people's self-reports. Concepts and measures of well-being and QoL have been controversial in the past in mental health research because they are not pathology based and because of the subjectivity of individuals' self-assessments – which might be distorted by symptoms (Katschnig 2005). Hence many measures include a proxy module for professionals and/or family carer assessments, although such evaluations might also reflect the subjective view of the assessors themselves. Some authors also prefer to include more 'objective' indicators of QoL (e.g. indicators of housing, employment and income) and emphasise the need for measures uncontaminated by mood states and cognitive disturbances (Eack and Newhill 2007). However, subjectivity is important in outcomes research: how the patient feels is important, rather than sole reliance on clinical indicators of how they ought to feel.

# Definitions of well-being and QoL

### **Defining well-being**

The World Health Organization (WHO) (1946) long ago recognised the importance of broader well-being to health in its definition of health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. The implication of this was that measurement of health should include well-being. The WHO also proposed that well-being can be assessed by measuring QoL (http://depts.washington.edu/seaqol/docs/WHOQOL\_Info.pdf; link valid 17 February 2014).

General well-being is a dynamic, multifaceted concept, and includes subjective, social, physical and psychological dimensions (Bowling 2009). The concept of subjective well-being emerged in the 1950s in attempts to move beyond reliance on objective indicators of QoL in the monitoring of social change (e.g. income, crime and housing quality) and towards more subjective measures, in order to more meaningfully reflect people's lives and experiences. This became the tradition of social indicators research (Noll 2004).

Classic models of well-being in social science have been based on the related but distinct concepts of 'the good life', 'evaluation of life satisfaction', 'subjective well-being', 'social well-being, 'morale', the balance between positive and negative affect, 'the social temperature' and 'happiness' (Gurin et al. 1960; Cantril 1965; Bradburn 1969; Andrews and Withey 1976; Campbell et al. 1976; Andrews 1986). They involve subjective self-assessments of:

- life satisfaction and/or morale (involving cognitive components in their evaluation)
- positive emotions such as happiness, involving an affective or emotional component (hedonic), reflecting the influence of early Greek and 19th-century utilitarian philosophy (Andrews and McKennel 1980; Bowling 2005)
- whether their life is meaningful (eudemonic).

Some models, especially in mental health, also include objective dimensions, assessed by self-reports (subjective in effect) or third party observations about whether basic needs have been met (e.g. housing and safety). The literature further divides subjective well-being into state (current well-being) and trait (well-being as a feature of character – which is less susceptible to interventions for change), and postulates that self-reported well-being measures reflect at least four factors: circumstances, aspirations, comparisons with others, and a person's baseline happiness or disposition (Warr 1999).

NHS Scotland more recently defined mental well-being (also referred to as psychological well-being in the literature) in terms of wider well-being, and as encompassing subjective feelings of life satisfaction, optimism, self-esteem, mastery and feeling in control, and having a purpose in life and a sense of belonging and support (NHS Scotland 2006).

In sum, mental, or psychological, well-being is usually conceptualised as some combination of positive affective states such as happiness (the hedonic perspective) and functioning with optimal effectiveness in individual and social life (the eudaimonic perspective) (Deci and Ryan 2008). These concepts are not identical, although many researchers continue to treat them as interchangeable and there is inconsistency in their use. Thus, while the concepts and measures of the different dimensions of well-being are related, and generally correlate highly, suggesting they tap a common underlying construct (Lohmann 1977), they are distinct concepts, and measurement scales have been developed for each of them. There is also a current awareness that well-being has no clearly defined opposite, and it is more than the absence of 'ill-being'. Huppert (2009, p.137) summarised the literature thus: 'Psychological well-being is about lives going well. It is the combination of feeling good and functioning effectively.' Thus there are no agreed definitions, other than that it is a 'good thing'. An agreed definition is needed, otherwise its effective precursors will remain unidentified.

Lay perceptions of these concepts are important to understand, if policy evaluation is to include social relevance. Lay perceptions of well-being, successful ageing, active ageing and quality of life have been elicited in separate national population surveys of adults and/or older adults. Considerable overlap between lay definitions of concepts was reported. For example, physical health and functioning, social relationships, social roles and activities, mental and cognitive functioning and psychological resources (including positive thinking and outlook) were the most common lay definitions of active ageing, successful ageing, QoL and well-being (Bowling 2006, 2008, 2011; Bowling and Dieppe 2005). These results support the use of broader definitions of each concept. The question of how well-being should be defined, and its components distinguished and measured, remains to be resolved (see overview by Dodge et al. 2012). An ongoing confusion in well-being research is its overlap with concepts and measurement of QoL.

### **Defining QoL**

The emphasis on evidence-based practice and patient/client-based outcome measures has led to an increase in the use of health-related (HR-QoL), disease-specific (DS-QoL) and generic (broader) measures of QoL in service evaluations.

### **Broader QoL**

As with well-being, there are many definitions of broader QoL and its constituents (Brown et al. 2004). There is also wide recognition of its subjective and multidimensional nature. QoL encompasses how an individual perceives the 'goodness' of multiple aspects of their life. Broader models of QoL were heavily influenced by the early social science literature on well-being and satisfaction with life (Andrews and Withey 1976; Campbell et al. 1976). But broader QoL is more than well-being. QoL is relevant in evaluating interventions – or assessing conditions – which

can affect a person's whole life, as in many chronic mental and physical illnesses. For example, Lawton (1983, 1991, 1994, 1997) developed a multidimensional concept of QoL, which encompassed elements of psychological well-being in addition to behavioural and social competence, perceived QoL and the external environment. Due to the proliferation of definitions of QoL, many investigators now refer to the WHO definition (WHOOOL Group 1993, p. 153; and see WHO 1995), as it is all-encompassing and captures the subjectivity and context of the individual: '... an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment'. The literature reveals that QoL encompasses self-evaluations of psychological well-being, as well as a wide range of more tangible life domains, including physical health and functioning, social support and resources, independence, material and financial circumstances, community social capital and the external environment (Brown et al. 2004).

### **HR-QoL**

HR-QoL is a broad multidimensional concept that usually includes self-evaluation of domains of life affected by one's health: '... the impact of a perceived health state on [living] a subjectively fulfilling life' (Bullinger et al. 1993). Following the WHO definition of health, HR-QoL has been defined as the physical, psychological and social domains of health which are influenced by a patient's experiences, beliefs and expectations of their condition and treatment (see Strand 1997). This focus distinguishes measures of HR-QoL and DS-QoL from broader QoL. A wide range of domains of HR-QoL have been identified, including:

- emotional well-being (e.g. measured with indicators of life satisfaction and self-esteem)
- psychological well-being (e.g. measured with indicators of anxiety and depression)
- physical well-being (e.g. measured with measures of physical health status and physical functioning)
- social well-being (e.g. measured with indicators of social network structure and support, community integration and functioning in social roles).

Some investigators prefer to use measures of QoL that are specific to diseases or conditions because they may be more sensitive to these diseases or conditions, although such use prevents comparisons being made across conditions. Definitions overlap with broader health status and include physical, mental, social and role functioning, and health perceptions (Ware and Sherbourne 1992).

# The definition and measurement of well-being and quality of life in mental health promotion and outcomes

### DS-QoL

DS-QoL focuses on areas of life directly influenced by a person's medical condition, and aims to quantify their subjective perceptions of the impact of the health condition on everyday life. Angermeyer and Kilian (2006) distinguished three models of QoL in the psychiatric literature:

- the 'subjective satisfaction model' the level of QoL experienced by an individual depends on whether or not their actual living conditions meet their needs, wants and wishes
- the 'combined subjective satisfaction/importance model'

   which considers different weights that different life
   domains may have in a person's QoL; individuals are invited
   to rate not only actual living conditions, but also their importance
- the 'role functioning model' the individual enjoys a good QoL if they can adequately perform common roles in life.

# Measuring well-being and QoL

It is recognised that psychosocial interventions contribute to the care of people with mental health problems and their families, and that this care encompasses a wide range of areas of life. There is thus interest in identifying relevant outcome measures which capture a broader range of relevant areas of life. For example, Moniz-Cooke et al. (2008) undertook consensus workshops, a pan-European consultation and a systematic literature review to identify the best, psychometrically sound outcome measures in the context of dementia, which can affect all areas of life. They identified 22 valid and reliable measures which covered QoL, as well as mood, global function, behaviour and skills in daily living.

An emphasis on mental health prevention and promotion (WHO 2002) has led to the need for broader outcome measures, rather than sole reliance on disease-based measures (e.g of psychological distress). As the WHO (2002, p. 7) recognised, mental health conditions affect an individual's functioning, resulting in a diminished QoL, emotional suffering, alienation, stigma and discrimination. The WHO (2002) described the levels of mental health prevention, and in 1986 defined mental health promotion as 'the process of enabling people to increase control over, and to improve their health' (WHO 1986; see also WHO 2002, 2005). It refers to positive mental health, rather than mental ill health. Strategies for mental health promotion are related to improving QoL and potential for health, rather than focusing solely on amelioration of symptoms. This has led to interest in measuring mental well-being. However, many established measures of broader QoL and DS-QoL (mental health) already include a mental well-being domain. Moreover, measures of QoL, HR-QoL and DS-QoL have accrued an enormous body of knowledge on their psychometric properties, and well tested measures, with a conceptual grounding, are available. There is a case for the use of broader OoL measures in relation to mental health

promotion and DS-QoL measures in the evaluation of service outcomes. Psychological well-being is a component of QoL, and psychometrically sound measures of broader QoL, as well as DS-QoL in mental health, have already been developed and are in widespread use.

Measures of the components of well-being and QoL should be used that are relevant to the target group, are psychometrically robust, capture positive and negative elements, are responsive to interventions and to changes in the QoL of the target group, and include a bottom-up, or co-design, approach, which can add value to service reconfiguration. This is required to ensure that the right things are being measured, to facilitate timely response from services, and for research on the effectiveness and costeffectiveness of service interventions. Whether an outcome measure is useful or not depends on its psychometric properties. Psychometrics is a well-established scientific field that is concerned with the evaluation of the properties of measures of subjective judgements. A good measure has robust evidence of its validity (does the instrument really measure what it purports to measure?) and reliability (is the measure stable and internally consistent?) and whether the sub-scales are supported by its factor structure.

Fitzpatrick et al. (1998) listed eight criteria that investigators should apply to evaluate patient-based outcome measures which are relevant:

- appropriateness (the match between the aims of the study and the instrument)
- reliability (the instrument should be internally consistent and reproducible)
- validity (the instrument should measure what it purports to measure)
- responsiveness (the instrument should be sensitive to changes of importance to patients)
- precision (the number and accuracy of distinctions made by an instrument)
- interpretability (how meaningful the instruments' scores are)
- acceptability (how acceptable do respondents find its completion?)
- feasibility (the amount of effort, burden and disruption to practitioners and services arising from the use of an instrument).

# Measuring psychological well-being

Well-being is a difficult concept to both define and measure overall; there is a lack of conceptual clarity in much of the literature. Well-being is generally measured subjectively, with measures consisting of people's own assessments of their overall lives, past and present, either cognitive (e.g. satisfaction) or affective (e.g. feelings of joy, pleasure and happiness) (Diener and Lucas 2000; Andrews 1974; Andrews and Withey 1976). There has been interchangeable use, without justification, of the distinct concepts within definitions of well-being, and hence measures. Morale and well-being are commonly categorised as components of mental or psychological well-being and measured using established and classic – although overlapping – scales of life satisfaction, well-being, or morale and affect (e.g. Campbell et al. 1976; Andrews and Withey 1976; Cantril 1965; Bradburn 1969; Neugarten et al. 1961; Wood et al. 1969; Dupuy 1984; Antonovsky 1993; Lawton 1972, 1975).

There have been calls for a greater focus on measurement of positive states, and not solely psychological distress (Winefield et al. 2012), as surveys have reported associations between positive emotional states and health (Xu and Roberts 2010; Boehm et al. 2011). The UK Office for National Statistics since 2011 has included four subjective well-being questions in household surveys, three of which were positive, and each tapping separate concepts of well-being (www.ons.gov.uk/ons/interactive/well-being-wheel-of-measures/index.html; www.ons.gov.uk/ons/dcp171766\_287415.pdf; links valid 17 March 2014):

- Overall, how satisfied are you with your life nowadays?
- Overall, to what extent do you feel the things you do in your life are worthwhile?
- Overall, how happy did you feel yesterday?
- Overall, how anxious did you feel yesterday?

Several specific life satisfaction scales have also been developed and are well tested (Neugarten et al. 1961; Diener et al. 1985, 2000, 2003).

Ryff (1989) has argued that existing prominent measures of psychological well-being have little theoretical grounding (these included measures of affect-balance, life satisfaction, self-esteem, morale, locus of control and depression). She conducted a survey using six existing measures of well-being and reported that key areas of psychological well-being derived from the literature were not strongly represented in these measures (positive relations with others, autonomy, purpose in life and personal growth). Ryff and Singer (1996) proposed, instead, a richer, multidimensional view of psychological well-being, including:

- autonomy
- environmental mastery
- personal growth
- positive relations with others
- purpose in life
- self-acceptance.

An example of a more recent measure is the Warwick-Edinburgh Mental Well-being Scale (WEMWBS), which was developed in the UK to measure population well-being and for use in evaluations of mental health promotion initiatives (Tennant et al. 2007). In contrast to negatively worded measures of mental distress, the developers deliberately included only positively worded items relating to different aspects of positive mental health. They regarded 'good mental well-being' to be more than avoiding mental health problems. The WEMWBS is a 14-item measure with five-point response scales, covering:

- optimism
- feeling useful
- relaxed
- interested in others
- energy
- dealing with problems
- thinking clearly
- feeling good about self
- feeling close to others
- confident
- able to make own mind up
- feeling loved
- interested in new things
- cheerful.

However, psychological well-being is not exactly at the opposite end of the continuum to psychological 'ill-being', or distress, indicating that research participants need to be asked about both (Winefield et al. 2012). Initial results for validity and reliability were judged to be good, based on a student survey (98% completed the well-being items) and Scottish population surveys (but a high proportion, 16%, failed to complete the well-being items). Confirmatory factor analysis supported the hypothesised one-factor solution, suggesting a one-factor scale structure (Tennant et al. 2007), and is responsive to change (Maheswaran et al. 2012). Given that the measure is composed of several distinct concepts, the single structure reported is questionable. Further robust psychometric studies are required. As Winefield et al. (2012) pointed out, that measurement of psychological well-being has been based on various instruments without any having gained dominance as a 'gold standard'.

# Measuring QoL

The increasing emphasis on evidence-based practice and inclusion of user-based outcomes in evaluative research has focused mostly on QoL outcomes. Maintaining people's broader QoL is a potentially important factor in ensuring that the person can 'live well' and that the care and support provided meet their needs. Several measures of DS-QoL, embedded largely within holistic models of functioning, life and needs satisfaction, have been developed for use with people with chronic and severe mental illnesses; many include a domain measuring psychological well-being (Thornicroft and Tansella 2010; WHO 2010).

Broader, multidimensional lay-based models and measures have also been developed for use at population level, and are likely to be more appropriate for use in mental health promotion. The most recently developed and well tested in both adult and older population samples are the CASP-19, OPQoL and WHOQOL.

#### CASP-19

The Control, Autonomy, Self-realisation and Pleasure (CASP-19) model was developed from the theory of human needs satisfaction and was tested with focus groups and a survey of people aged 65–75 (Hyde et al. 2003). It concentrates on four theoretically derived (19 items): control (four items), autonomy (five items), pleasure (five items) and self-realisation (five items), with four-point Likert response scales (from 'Often' to 'Never'). It was developed for use with an older population sample, but has also been used in several large population surveys, including the English Longitudinal Survey of Ageing (ELSA) (Blane et al. 2008).

### **OPQoL**

The Older People's Quality of Life (OPQoL) questionnaire is unique in being developed from a national sample of older people's responses to open-ended questioning and during indepth interviews about the 'good things' that gave life quality (Bowling et al. 2003; Gabriel and Bowling 2004). The main themes mentioned, and included in the OPQoL, were:

- social relationships
- social roles and activities
- activities/hobbies enjoyed alone
- health
- psychological outlook and well-being
- home and neighbourhood
- financial circumstances
- independence.

Long and short versions have been developed and tested in national population samples, ethnically diverse samples of people aged 65 and over, and hospital outpatients (Bowling and Stenner 2011; Bowling et al. 2013; Bilotta et al. 2011).

### **WHOQOL**

The structure of the WHO's QoL questionnaire reflects the issues that groups of scientific experts and lay people felt were important to QoL. Full length (Power et al. 1999) and shorter (WHOQOL Group 1998) versions have been developed and tested, as well as a version for older people (WHOQOL-OLD) (Skevington 1999; Power et al. 1999, 2005). The domains of the full WHOQOL include:

- health (physical health, energy/fatigue, pain/discomfort and sleep/rest)
- psychological (including bodily image and appearance, negative feelings, positive feelings, self-esteem, thinking, learning, memory and concentration)
- independence (mobility, activities of daily living, dependence on medicinal substances and medical aids, and work capacity)
- social relations (personal relationships, social support and sexual activity)
- environment (financial resources and freedom/physical safety/security)
- health and social care (accessibility and quality)
- home environment (opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure, physical environment (pollution/ noise/traffic/climate) and transport)
- religion/spirituality/personal beliefs.

#### **HR-OoL**

A commonly used proxy indicator of HR-QoL is the short-form 36 health status questionnaire (SF-36) or its shorter versions (Ware et al. 1993, 1996, 1997). While the SF-36 was developed to measure broader health status, its components overlap with HR-QoL in relation to mental, physical and social functioning. However, caution is needed: health and QoL are distinct concepts, and are perceived differently by lay people (Smith et al. 1999). The broader WHOQOL is also used to measure HR-QoL, and has been used in population studies, healthcare evaluations and clinical trials (WHOQOL Group 1998).

# DS-QoL in mental health

The importance attached to measuring QoL in mental health is reflected in the wide range and number of tools that have been developed to measure this concept in people diagnosed with conditions from schizophrenia to depression (Lehman and Lasalvia 2010). Many measures include proxy versions, which also reflect biased assessments; agreement between self-assessments and proxies is generally weak to modest (Becchi et al. 2004).

Significant developments in QoL measurement in mental health in the UK were made in the late 1980s with the development of the Lancashire Quality of Life Profile (LQoLP) by Oliver and colleagues. Taking issues of definition and measurement into consideration, the LQoLP (Oliver et al. 1996; van Nieuwenhuizen et al. 2001) was carefully developed from the US Quality of Life Interview (Lehman et al. 1982; Lehman 1983a, 1983b, 1988). The LQoLP combines objective and subjective measures within several life domains. It was developed in response to a UK governmental requirement to assess the impact of community care programmes on the QoL of patients, with good internal consistency, construct, content and criterion validity (Oliver et al. 1996, 1997; Hansson et al. 1998; Gaite et al. 2000; van Nieuwenhuizen et al. 2001). It is a structured self-report interview (administered by trained interviewers) and includes a proxy version for carers. It includes:

- work and education
- leisure and participation
- religion
- finances
- living situation
- legal status and safety
- family relations
- social relations
- health.

It includes established measures of components of psychological well-being:

- subjective life satisfaction scale
- positive and negative affect scale (Bradburn (1969) Affect-Balance Scale)
- self-esteem scale (Rosenberg 1965)
- global well-being (two items from Cantril (1965))
- a happiness scale (Gurin et al. 1960)
- the Quality of Life Uniscale (Spitzer and Dobson 1981)
- the perceived Quality of Life Score, an average of the sum of the subjective items of the first nine domains.

By including distinct measures of these components of well-being, the LQoLP avoids the criticism of ignoring their distinctness. It is lengthy, and thus the Manchester Short Assessment of Quality of Life was developed with the aim of producing a shorter version of the LQoLP, containing four objective and 12 subjective questions (Priebe et al. 1999). Just some of the many other DS-QoL instruments used in the psychiatric field include the Quality of Life Index for Mental Health (Becker et al. 1993); the Wisconsin Quality of Life Index (Diamond and Becker 1999); the Oregon Quality of Life Questionnaire (Bigelow et al. 1982); and the Quality of Life in Depression Scale (Hunt and McKenna 1992). For reviews of measures see Lehman and Lasalvia (2010) and Gigantesco and Guiliani (2011).

### Conclusion

In sum, QoL is a complex concept characterised by multidimensional aspects. Numerous studies recognise it as an important and reliable measure for assessing the wider outcomes of individuals suffering from mental disorders. A wide spectrum of well-tested DS-QoL (mental health) measures is available. Broader measures of QoL are also of value in mental health promotion. As Gigantesco and Guiliani (2011) point out: 'An increased surveillance of the variables associated with higher levels of QoL in general population may be potentially important from a public health policy point of view because improving QoL may have benefits for mental health and disease prevention.'

# The definition and measurement of well-being and quality of life in mental health promotion and outcomes

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# Mental health research in the National Institute for Health Research

**Author** Alison Tingle<sup>1</sup>

1 Research Analyst, Department of Health

# Background

Investment in mental health research has been subject to scrutiny/analysis for a number of years. In 2010, the Medical Research Council (MRC) published a comprehensive review of mental health research in the UK.¹ While the report acknowledged obstacles to progress, it also recognised opportunities for mental health research to build on a number of key research strengths, including the UK's major strength – through the alliance of the National Institute for Health Research (NIHR), the MRC and the devolved administrations – in translating research into health and economic benefits. The latter is facilitated by the Office for Strategic Coordination of Health Research through its strategic co-ordination of health research and coherent funding arrangements.

More recently a new UK-based charity, MQ, has been established by Lord Stevenson and backed by a £20 million start-up pledge from the Wellcome Trust, whose key focus is on identifying and funding research that is crucial to solving global issues in mental health. Aiming to be the mental health equivalent of Cancer Research UK, the charity has already set up a Fellows Programme to support the most promising early career scientists and clinicians.

# Mental health research in the NIHR

The Department of Health's (DH) Research and Development Directorate supports research on mental health through the NIHR, the DH Policy Research Programme and in partnership with other funders. The NIHR commissions and funds leading-edge NHS, social care and public health research, driving faster translation of basic science discoveries into tangible benefits for patients and the public.

Mental health is the third largest area of NIHR spending (£70 million), with just cancer (£133 million) and research of 'generic health relevance' (£114 million) more prominent. Mental health research spend over the period has increased, with more funding going to NIHR research programmes, infrastructure and training. This represents an increased focus on the health research system as a whole, rather than research being skewed by an injection of funding into a particular part. The following are examples of recent research spend:

- There have been significant increases in mental health research spending across most NIHR programmes, including Health Technology Assessment, Health Service and Delivery Research, Efficacy and Mechanism Evaluation, and Research for Patient Benefit.
- The new Biomedical Research Centre (BRC) contracts for the period 2012–2017 have resulted in a substantial increase in BRC mental health spending.
- There has been a substantial increase in funding through the Clinical Research Network; this will be driven by directly funded NIHR research and by research funded externally by research councils and charities.
- Mental health is the largest disease-specific area funded through NIHR research training awards.

# Building enhanced research capacity to exploit scientific opportunities in mental health

General psychiatry is a strong element within the NIHR Integrated Academic Training Programme. Two psychiatric specialties (forensic and old age) were part of a 2012 competition for additional academic clinical fellow (ACF) posts to address NIHR priorities. Academic psychiatry has generally been successful in accessing NIHR support, as shown by the following examples:

- In total, 62 ACFs were recruited between 2008 and 2011 (midway in the distribution of specialties when ranked according to the ratio of ACFs to CCTs). Of these, 60 were recruited in general psychiatry, two in forensic psychiatry and one in old age psychiatry.
- A total of 17 clinical lecturers were appointed over this period: 16 in general psychiatry and one in forensic psychiatry. This compares well with other specialties.
- Six current NIHR staff hold personal awards: four clinician scientists (two in general psychiatry, one in childhood and adolescent psychiatry and one in old age psychiatry); one NIHR post-doctoral fellow in childhood and adolescent psychiatry; and one doctoral research fellow in forensic psychiatry (a former ACF).
- Old age psychiatry (dementia) and forensic psychiatry were priorities in the 2011/12 and 2012/13 Integrated Academic Training recruitment rounds.

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# **Further information**

Chapter 6 'Life course: children and young people's mental health'

# NICE Guidelines relating to children and young people

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# **Further information**

Chapter 16 'Addictions, dependence and substance abuse'

### Further sources of information

#### Alcohol

www.gov.uk/search?q=alcohol Government web pages on alcohol

### www.alcohollearningcentre.org.uk

PHE Alcohol Learning Resources – online resources and learning for commissioners, planners and practitioners working to reduce alcohol-related harm

www.rcplondon.ac.uk/projects/alcohol-health-alliance-uk
The Alcohol Health Alliance is a coalition of health
organisations in the UK concerned with alcohol-related harm
and public health policy, overseen by the Royal College of
Physicians

### www.alcoholresearchuk.org

Alcohol Research UK – supports alcohol research and the dissemination of evidence

### www.nta.nhs.uk/ndtms.aspx

Alcohol treatment data from PHE's National Drug Treatment Monitoring System

#### www.alcoholconcern.org.uk

Alcohol Concern – national charity on alcohol issues

### www.ias.org.uk

The Institute of Alcohol Studies provides independent evidence on trends in alcohol consumption and related harm in the UK

www.who.int/substance\_abuse/publications/global\_alcohol\_report/en

WHO global trends in alcohol consumption and related harm

### **Tobacco**

www.ash.org.uk

Action on Smoking and Health

<u>www.gov.uk/government/policies/reducing-smoking</u> Department of Health

### www.smokinginengland.info

Latest information on smoking and smoking cessation in England

www.lho.org.uk/LHo Topics/analytic Tools/

<u>Tobaccocontrolprofiles</u>

Local Tobacco Control Profiles for England (London Health Observatory)

#### www.ncsct.co.uk

NHS Centre for Smoking Cessation and Training

### www.rcplondon.ac.uk/resources/topic/258

Royal College of Physicians Tobacco Advisory Group reports

http://resources.smokefree.nhs.uk/resources

Smokefree resource website (Department of Health)

### www.hscic.gov.uk/catalogue/PUB11454

Statistics on smoking in England

#### www.treatobacco.net

Treatobacco, an authoritative evidence review of the treatment of tobacco dependence (includes a new section on e-cigarettes at

www.treatobacco.net/en/page 492.php)

#### www.ukctas.ac.uk

UK Centre for Tobacco and Alcohol Studies

#### www.who.int/fctc

WHO Framework Convention on Tobacco Control

#### www.who.int/tobacco

WHO Tobacco Free Initiative

### **Opiates**

Government web pages on reducing drug misuse and dependence

www.gov.uk/government/policies/reducing-drugs-misuseand-dependence

PHE's Alcohol, Drugs and Tobacco Division – guidance and data on drug misuse prevalence, treatment and prevention www.nta.nhs.uk

PHE's Health Protection Directorate – data and advice on infections associated with drug misuse <a href="https://www.hpa.org.uk">www.hpa.org.uk</a>

Office for National Statistics annual reports on drug poisoning

www.ons.gov.uk/ons/rel/subnational-health3/deaths-related-to-drug-poisoning

European Monitoring Centre for Drugs and Drug Addiction – provides the EU and its member states with data, evidence and best practice on European drug problems <a href="https://www.emcdda.europa.eu">www.emcdda.europa.eu</a>

DrugScope – a UK charity supporting professionals working in drug and alcohol treatment, drug education and prevention and criminal justice

www.drugscope.org.uk

### **Benzodiazepines**

NHS Prescription Division of the NHS Business Authority <a href="https://www.nhsba.nhs.uk/PrescriptionServices.aspx">www.nhsba.nhs.uk/PrescriptionServices.aspx</a>

Committee on the Review of Medicines. Systematic review of the benzodiazepines.

http://www.benzo.org.uk/commit.htm

NICE scenario covering the assessment of a person who is being prescribed long-term benzodiazepines or z-drugs, and offers advice on managing withdrawal of treatment. http://cks.nice.org.uk/benzodiazepine-and-z-drug-withdrawal

National Addictions Centre, King's College London www.kcl.ac.uk/iop/depts/addictions/index.aspx

Appendix 5 Recommendations

# Recommendations

Where

APMS Adult Psychiatric Morbidity Survey
CCGs Clinical Commissioning Groups

DH Department of Health

HEE Health Education England

HSCIC Health and Social Care Information Centre

HWBB Health and Wellbeing Boards

LAs Local Authorities

MHIN Mental Health Intelligence Network

ONS Office for National Statistics

RCGP Royal College of General Practitioners

RCPsych Royal College of Psychiatrists

Recommendation		Organisation
1	Commissioners in Local Authorities, Health and Wellbeing Boards and Clinical Commissioning Groups should follow the WHO model in commissioning and prioritising evidence based interventions for mental health promotion, mental illness prevention and treatment and rehabilitation. Well-being interventions should not be commissioned in mental health as there is insufficient evidence to support this.	CCGs Commissioners in LAs HWBB Public Health England
2	All Health and Wellbeing Boards should be informed by a Joint Strategic Needs Assessment (JSNA) which includes the information needed to plan services to integrate the mental and physical health needs of their populations. The required information is provided for ease of access by the Mental Health Intelligence Network.	HWBB
3	The Outcomes Frameworks should work together to develop a metric that recognises patient experience of the integration of their care and leads to rewards for effective integration around the patient's health and social care needs.	DH
4	The Torbay and South Devon Integrated Care Pioneer service in primary care psychiatry should be evaluated with a view to further development and piloting elsewhere in England.	NHS England RCPsych RCGP
5	I recommend that arrangements put in place for mental health data collection are not different to those put in place for physical health, in keeping with the stated policy of parity.	HSCIC MHIN NHS England
6	Employment is central to mental health and it needs to be a routine part of patient records. So, the Health and Social Care Information Centre, working with the Royal College of General Practitioners and other Royal Colleges, should review the existing taxonomy for the routine collection of employment data to ensure that it is usable and can be coded across all care settings. Employment status should then become a routine part of all patient records.	HSCIC Royal Colleges
7	I recommend that the ONS continue to work with expert psychometricians as they further develop the Measuring National Wellbeing Programme and all other related activity.	ONS

Recommendation		Organisation
8	The Mental Health Intelligence Network should link routine mental health data to longitudinal mental health survey data to better understand patterns of mental illness across the community, including those affected by the 75% treatment gap.	DH
		MHIN
		Public Health England
9	NICE should analyse the cost benefit of providing a fast and efficient integrated pathway for psychiatric provision for people with mental illness, who risk falling out of work, aimed at maximising their ability to stay in work.	NICE
10	I recommend that there should be a period of specific mental health training in GP training. A core part of the training should include specific training for awareness about the consequences of violence on mental health across the life course.	HEE
		RCGP
11	I recommend that Health Education England should publish a report in 2015 on progress against its target of 45% of Foundation Year doctors undertaking a post in psychiatry from 2014-15 onwards.	HEE
		RCGP
12	If GPs suggest using new technologies to improve mental health to patients they should draw these from an approved list of NHS evaluated technologies which have met the standards required by evidence based medicine.	RCGP
13	I recommend that the evidence based 'Time to Change' programme should continue to be funded and should continue to involve and empower 'people with lived experience'.	DH
		Time to Change
14	I recommend that NHS England develop a programme of work to agree waiting times and access standards across mental health services, starting with the collection and publication of robust national data to underpin the development and implementation of this programme.	NHS England

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Kamlesh Patel

Matthew Patrick

TVIGICITE VV T GETTER

Rachel Perkins Martin Prince

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Sian Rees

Wendy Reid

Jamie Rentoul

Jonty Roland

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