

Annual Report of the Chief Medical Officer, 2014

The Health of the 51%: Women



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Department
of Health

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Jean Reader

I publish my annual report in two volumes each year: a 'surveillance' volume which provides an epidemiological picture of the public's health, and an 'advocacy' volume which presents recommendations for action to benefit the public's health. As the first woman Chief Medical Officer I am delighted to produce this report which concentrates on the health of women and associated taboos.

A woman's life course offers multiple opportunities to prevent predictable ill-health, and address predictable problems. I want to ensure that the many 'taboo' subjects are discussed more easily. Women should feel confident to ask about the variety of ways they can best manage symptoms of incontinence and menopause. Employers can lead the way here by making it more acceptable for female staff to discuss health issues in the workplace. Embarrassment should never be a barrier to better health.

Tackling obesity in the whole population is an accepted public health priority. However, I advocate recognising obesity at the level of a "national risk". I congratulate all those committed to tackling obesity and improving weight management (at both professional and personal levels) and I look forward to seeing government action through 2016 to tackle obesity.

Sally C Davies

Prof Dame Sally C Davies

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Chapter 1

Chief Medical Officer's summary

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Introduction

Being the first woman Chief Medical Officer has played a part in my decision to focus this, my fourth advocacy report, on women's health. There are often issues that are not talked about — even ignored. Yet a woman's life course offers multiple opportunities to prevent predictable morbidity and mortality and to empower women (and, through them, their families) with information to take positive steps towards health.

Problems 'below the waist' are not generally seen as attractive topics for public or political discourse. Women are often reluctant to seek help for conditions that are common, disabling and taboo, such as urinary and faecal incontinence and menopausal symptoms. Violence affects women in England's physical and mental health on a scale which demands action across society. We must be able to talk about these issues so, in this report, I advocate increased awareness, dissemination of information and person-centred care in order to help women with hidden morbidity improve their quality of life.

Education on sex, relationships, planning a family and general health is patchy and, where it does exist, it often needs improvement. I hear frequently how the availability of evidence-based, cost-effective contraception has been affected by restrictions on the basis of age and by fragmentation of services. Contraception services and pre-conception planning are not linked! Meanwhile, data are lacking on women's physical and mental health before, during and in the years after pregnancy and linkage of existing data to other datasets is limited.

Tackling obesity in the population as a whole has to be a national priority, in order to reduce the impact of related, non-communicable diseases on healthy life expectancy and health services. Reducing obesity in women also has the potential to lower the chances that their children will be obese.

Measures to address many of these problems are within our reach: in areas such as women's cancers, a fall in mortality in cervical cancer has followed the introduction of the national screening programme and there will likely be further reduction in the future with the national Human Papilloma Virus vaccination programme. Maternal mortality has fallen year on year to its lowest-ever level.

This report covers violence against women, women's health in their reproductive years and women's health in later life. There will always be some areas that cannot be covered due to space constraints, for example, dementia (due to their longer life span dementia affects more women than men).

In the chapters of this report, following my previous report *Public mental health priorities: investing in the evidence*, I give

parity of esteem to mental and physical health. Neither can or should be ignored, nor considered in isolation.

As the chapters of this report came together, the issue of obesity came to the fore as a common theme. A healthy Body Mass Index (BMI) is 18.5–24.9, obesity is defined as a BMI >30. The prevalence of obesity is over 25% in both women and men. It is associated with leading causes of morbidity and mortality, such as diabetes, cardiovascular disease and cancers.

In women obesity can affect the outcomes of any pregnancies they have and impacts on the health of any future children they may have. In pregnant women, the developmental environment can affect the fetus and its germline cells, e.g. their eggs (primary oocytes) and so a woman's health whilst she is pregnant also impacts on the health of her children and grandchildren. This is a difficult message to convey, as it risks burdening women with guilt and onerous responsibility; I believe, however, that it can also empower women to take positive steps to healthy, stable nutrition and physical activity to benefit themselves and their families.

Action is required for women and across society to prevent obesity and its associated morbidity and mortality from overwhelming our health and social care resources and reducing England's productivity. We must redouble our efforts to address education and environmental factors, across government, healthcare and wider society, while encouraging a greater degree of personal responsibility.

Recommendation 1

I recommend that the Government includes obesity in its national risk planning.

Violence against women

Chapter 2 Gender-based violence against women

Chapter 3 Female genital mutilation

Young men are the group most likely to be affected by violence, however women are more likely to be affected by domestic abuse and sexual violence. Amongst victims of homicide, women are far more likely to be killed by partners or ex-partners (46% of women killed vs. 7% of men killed).

Violence against women is prevalent at levels which make any ideals of ours as a civilised society difficult to reconcile with the reality. This violence impacts on the mental and physical health of women and also their children. In England, violence against women must be considered as a determinant of health by those planning and delivering healthcare.

The prevalence of violence is collected annually in the *Crime Survey for England and Wales* (CSEW), as well as in other surveys such as the *British National Survey of Sexual Attitudes and Lifestyle* (NATSAL). There is no need to exaggerate the scale and impact of this violence which is reported in the public domain: in the 2013/14 CSEW, 2.2% of women (approximately 355,000) aged 16–59 had experienced some form of sexual assault in the last year and 8.5% of women (1.4 million) had experienced domestic abuse. Violence against women is associated with physical injury, sexually transmitted infections, pregnancy, post-traumatic stress disorder (PTSD), sexual and mood disorders, self-harm and suicide. In England and Wales lifetime rates of violence against women are one-third higher than the European Union average, which begs the question why?

Certain groups of women are more likely to experience violence. For example, sex workers have an increased risk of physical and sexual violence and have a higher mortality than the general population. Some 95% of women trafficked into England for sex work have experienced physical and sexual violence. I note recent human trafficking and exploitation legislation passed in Northern Ireland which includes a clause criminalising paying for sex and the concern that this will have detrimental consequences for the safety and health of sex workers.

Migration is currently at the forefront of our minds as the European Union is faced with the large increase in those seeking residence, asylum or both. In a survey of women asylum seekers, detained at Yarl's Wood, three quarters reported having been raped prior to seeking asylum and nearly half reported experiencing torture. The mental and physical health of those held in detention centres deteriorates, particularly for survivors of torture with Post-traumatic stress disorder (PTSD). This is exacerbated by poor access to reproductive healthcare and mental health services. There is also a lack of policy-relevant evidence as to the health needs of asylum seekers.

To address the needs of women affected by violence, we need to ensure the awareness of healthcare workers and their access to appropriate training. Safe disclosures by women, with clear pathways for referral, are essential to protect women and their children from further harm. These must be underpinned by an understanding that violence against women is a determinant of mental and physical health. Education on violence against women needs to start at the undergraduate level so that healthcare workers consider it amongst the determinants of health. Educational materials should also be available for postgraduate healthcare professionals to continue their learning as they practise.

Recommendation 2

I recommend that the General Medical Council ensures that medical undergraduate training equips future regulated doctors to recognise and respond to violence against women, and that other regulators (General Dental Council and Nursing and Midwifery Council) ensure this issue is given due prominence.

Recommendation 3

I recommend that Health Education England e-learning modules (such as the newly developed set for female genital mutilation and those for domestic violence and modern slavery) be:

a) developed for sexual violence, 'honour'-based violence and forced marriages

b) freely available to all regulated healthcare professionals via the e-learning for health portal and portals used by other health and social care professionals and that there is continuing professional development credit for doctors in this area.

There is a danger that increased recognition of the role of violence as a determinant of health will lead to increased referrals and I am concerned that women may come to harm if services are not able to meet this demand. Increased referrals could overwhelm specialist services, which may not have the capacity to handle them safely. Additionally healthcare workers, who often move during their training and may work in the community or from multiple sites, may not be aware how to safely refer women affected by violence to specialist services.

Recommendation 4

I recommend that Clinical Commissioning Groups and local authorities ensure that integrated specialist health and social care services are in place to meet referrals safely for sexual violence, other domestic violence, female genital mutilation, 'honour'-based violence, forced marriages and modern slavery.

Recommendation 5

I recommend that acute hospitals, mental health services and GP practices provide information on referral pathways for violence against women at their workplace inductions for healthcare professionals.

It is estimated that 127,000 women in England are living with female genital mutilation (FGM). Mental illnesses such as depression and anxiety have been associated with FGM; psychological services to address these should be evaluated. Women living with FGM have higher rates of pain during sex and may experience absence of sexual desire. Their pregnancies have increased rates of bleeding after delivery and they have increased rates of perinatal death. They may also be less likely to access other services, such as cervical screening.

Protection of girls is important and awareness and attitudes in the diaspora communities need to be better understood. FGM occurs in some, but not all, countries in Africa, the Middle East and Asia; the extent to which families from these countries living in England intend to have FGM performed on their children has not been assessed. At present, all female children in these families are assumed to be at potential risk.

Recommendation 6

I recommend that the social science community applies to the Economic and Social Research Council for funding to investigate relevant social issues and how to change attitudes to FGM in diaspora communities in England from countries where female genital mutilation is practised.

Women's health in the reproductive years

Chapter 4	Eating disorders
Chapter 5	Pre-conception health
Chapter 6	Prenatal screening
Chapter 7	Perinatal mental health
Chapter 8	Post-pregnancy care: missed opportunities during the reproductive years

Women have a higher lifetime prevalence of eating disorders than men. An overconcern about eating, body shape and weight underlies many of the eating disorders. Those with eating disorders often also have depressive or anxiety features and may develop physical complications. The mortality rate is doubled in sufferers of bulimia nervosa and increased six-fold in sufferers of anorexia nervosa. It is important that treatment is accessed early in the course of the eating disorder, as recovery is more likely at the stage before the eating disorder becomes self-perpetuating and complications have developed. The announcement of further funding for services in the 2014 Autumn Statement is welcome; these services must be evidence-based and available in all areas.

Recommendation 7

I recommend that Clinical Commissioning Groups ensure prompt access to evidence-based enhanced cognitive behaviour therapy (CBT-E) and family-based therapy for eating disorders. This should be available in all areas, as in the NICE guidance, and not restricted to specific age groups.

Around 80% of women will give birth. The chapters in my report on women's health before, during and after pregnancy are related. Women who become pregnant will move through the areas covered by these as they plan for and become pregnant, and then as they go through the postnatal period back to 'normal' physiology. On average, women spend over 30 years needing to avert an unplanned pregnancy.

Pregnancy can reveal conditions such as diabetes and hypertension which can manifest due to gestational changes in physiology years ahead of when they might otherwise have become apparent. Pregnancy is also a time when women engage with healthcare professionals and are motivated to make positive changes. From the evidence presented in this report, it is clear that in England a missed opportunity exists for delivering health messages for the short- and long-term mental and physical health of mothers and their children.

The 1999 National Teenage Pregnancy Strategy aimed, by 2010, to halve the rate of conceptions among under-18s in England and set a firmly established downward trend in the conception rates for under-16s; the under-18 conception rate reduced by 41% from 1998–2012, due to a sustained effort by local government, health partners and individual practitioners. Young women and men could be made aware of concepts and

could build on this understanding to considerably improve their own health – and that of future generations!

Responses to the National Survey of Sexual Attitudes and Lifestyles indicated that the three sources that 16–24-year-olds preferred to get sex and relationships education from were schools, parents and healthcare workers. Evidence shows that sex and relationships education (SRE) does not lower the age of first sexual intercourse and in many studies has been shown to delay it. We need to agree the role of the state in providing the model for what a 'healthy relationship' is, and how best to involve parents in decisions about the content of SRE and to signpost the relevant healthcare services. SRE is recommended by the Department for Education (DfE) to be delivered as part of a programme of personal, social, health and economic (PSHE) education.

Changes to the curriculum for PSHE education should be evidence-based, and health sections should include material such as: effective information on interventions to maintain a healthy weight through nutrition and physical activity; the positive impacts of healthy decisions in youth on later life health and that of the next generation; family planning and pathways to access information and contraception services; and bystander interventions to reduce violence against women. The potential reduction of morbidity and mortality, in women and any children they have, from interventions at this stage are considerable. PSHE should empower children with the information that they need to plan healthier lives. I note the Education Select Committee's recommendation for statutory PSHE, the DfE's responses and the bill for statutory PSHE introduced by Caroline Lucas MP, which will have its second reading in 2016.

Recommendation 8

I recommend that the Department for Education and Department of Health together make integrated personal, social, health and economic education (PSHE) with sex and relationships education (SRE) a routine and, if necessary, statutory part of all children's education.

In April 2012, the Advisory Group on Contraception published *Sex, lives and commissioning: an audit of the commissioning of contraceptive and abortion services in England*. This showed that, in many areas, access to the full range of contraception (including long-acting reversible contraceptives, which the National Institute for Health and Care Excellence has advised are cost-effective) is restricted to the under-25 age group. Areas with restricted access were shown to have relatively higher abortion rates. Conception rates are rising in older age groups, as are the rates of abortion, indicating unplanned pregnancies. Contraception services are now funded by local authorities and Clinical Commissioning Groups (CCGs) as a public health service and there appears to be a lack of cross-system leadership to ensure provision of evidence-based contraception services to all the women that need it.

Recommendation 9

I recommend that NHS England, Local Authorities and Clinical Commissioning Groups in their system leadership role should ensure provision for a full range of contraception services to all women, that is person centric and at all reproductive ages.

Basic data regarding the health of women before, during and after pregnancy, eg BMI at booking for maternity care, have not been routinely collected until recently. The National Maternity Services Dataset started this process from June 2015, with linkage to infant outcomes. Electronic healthcare records are planned for use across the NHS from 2020, and from 2018 it is planned that patients will be able to access and edit their care record. Electronic records can be developed to provide the most useful possible data to evaluate pre-conception health interventions (such as PSHE and SRE), use the outcomes of pregnancy to plan women's future health and support research into women's health.

Recommendation 10

I recommend that the Royal Colleges of Obstetricians and Gynaecologists, Midwives and Paediatrics and Child Health and the Department of Health, should jointly convene a meeting of stakeholders to determine the optimal data items, assessment tools and linkage to child outcomes to capture information about women's mental and physical health before, during and in the years after pregnancy.

Pre-natal screening improves the detection of pregnancies at risk of adverse outcomes and accounts for only £4 million of the annual £2.5 billion maternity care spend in England. The exemplar of pre-natal screening is Down syndrome screening, which has reduced the number of babies born with Down syndrome to 54% of the predicted number. I note that the National Screening Committee will examine the evidence for gestational diabetes mellitus screening with the results of a health technology assessment, due later this year. Pregnancy complications for which the evidence has not, to date, supported pre-natal screening incur large burdens of morbidity, mortality and costs to society. Pre-eclampsia incurs £9,000 in immediate additional costs per affected pregnancy, the additional direct costs of delivering a baby with fetal growth restriction are approximately £2,650 while infants born below the third centile for birth weight have double the rate of special educational needs at school. Pre-term birth in the UK incurs direct costs of £1.24 billion and indirect costs of £2.48 billion annually and is the major cause of neonatal deaths of normally formed babies. Stillbirth is higher in the UK as compared with other high-income countries.

I also note that indemnity against litigation in maternity adds £700 to the cost of every delivery and accounts for 34% of the NHS Litigation Authority budget. The insufficient evidence to support screening for these prevalent and costly causes of morbidity and mortality for mothers and children

is due to a lack of underpinning research. Anecdotally, there is also a lack of private sector/industry funding in this area, which compounds the problem. We need research in these areas, as well as into the aetiology, diagnosis and treatment of pregnancy complications.

Recommendation 11

I recommend that the UK Clinical Research Collaboration works with research funders to review the research needs and spend in the area of pregnancy. Particular research areas highlighted in this report include:

- **pre-conception interventions to improve maternal and child mental and physical health**
- **screening tests, prevention and treatment for pre-eclampsia, fetal growth restriction and pre-term birth**
- **optimum models for antenatal and postnatal care.**

Baroness Cumberlege is currently chairing a review of maternity services in England, set up after the tragic failings identified at Morecambe Bay. I support the aims of the review to 'ensure that the NHS supports and enables women to make safe and appropriate choices of maternity care'. The current model of postnatal care is not fit for purpose and there is little research into alternative, safe and cost-effective models. Without further research, there will not be evidence-based alternatives for the review to recommend.

At present, planning for a healthy pregnancy by individuals and their supporting healthcare professional is inconsistent, even for those with co-morbidities who would benefit from pre-conceptual counselling and advice. There is also minimal planning for the postnatal period during pregnancy, eg for contraception, when women are probably most motivated to make positive decisions for their health and that of their children. The transfer of information on the outcomes and complications of pregnancy from secondary to primary and community care is reported as inconsistent, while breastfeeding rates of 1% at six months (the minimum period for exclusive breastfeeding recommended by the World Health Organization) reflect a failure to support an essential activity for infant and maternal health.

The triennial national audits into maternal mortality have identified that perinatal mental illness has remained a leading cause of maternal death in England. Affecting one in five women at some point during pregnancy and the postnatal period, mental illness is among the most common morbidities of childbearing. Health professionals training in perinatal mental health are limited and specialist services are available to only half of the population; only 3% of CCGs reported that they had a strategy for commissioning specialist perinatal mental health services. The NHS England perinatal commissioning guide, currently in draft, needs to address capacity to ensure timely access to specialist services.

Smoking is the single biggest modifiable risk factor for poor birth outcomes and a major cause of inequality in child and maternal health. While rates of smoking during pregnancy are reducing across England, there are some parts of the country where levels remain stubbornly high. I therefore welcome the news that Public Health England is exploring opportunities to pilot highly targeted social marketing approaches in areas with a high prevalence of smoking in pregnancy.

Recommendation 12

I recommend that NHS England and Clinical Commissioning Groups ensure that all women have prompt access to evidence-based psychological interventions for perinatal mental disorders, a local perinatal mental health service and regional mother and baby inpatient units.

The stigma attached to perinatal mental disorders may prevent women from seeking help, or they may be worried that mental illness is not compatible with being a good mother and that their baby will be taken away from them. Measures to address stigma and public awareness and to improve health and social care workers' responses to perinatal mental illness could facilitate more women to access prompt treatment.

At present, the Mental Health and Learning Disabilities Dataset does not include pregnancy. The addition of this would provide useful data to audit commissioning and delivery of services and would support research into perinatal mental health.

Recommendation 13

I recommend that the Health and Social Care Information Centre modifies the Mental Health and Learning Disabilities Dataset (v.1.0.12) to include pregnancy and the post-partum year.

Women's health in later life

Chapter 9 The psychosocial impact of the menopause

Chapter 10 Urinary and faecal incontinence and prolapse: pelvic floor dysfunction

Millions of women are affected by morbidity which may be embarrassing to talk about and convenient for healthcare professionals to ignore, such as urinary and faecal incontinence, prolapse and the transition to the menopause. Awareness of the importance of open discussion of these issues for both the public and healthcare professionals is likely to be key in addressing the needs of women who may otherwise live with considerable impairment to their lives.

All women go through the menopause; in England, the average age of onset is 51 years. Symptoms of the menopause usually last between four and eight years. Evidence indicates that approximately 20-25% of women will have vasomotor symptoms which adversely affect their perceived quality of personal and working lives. NICE guidance published in November 2015 gives an up-to-date review of the evidence for clinical diagnosis and treatment of the menopause. There are simple self-help measures which women can take ahead of and during the menopause to improve their experience. Non-pharmaceutical treatments such as cognitive behavioural therapy are helpful in reducing the impact of menopausal symptoms.

There were 3.5 million women aged 50–65 in employment in 2013, however women report that they do not feel able to discuss the issues of menopausal symptoms affecting their performance at work with their employer. Evidence-based advice for employers and women at work will help women working during the transition to the menopause. With an ageing national workforce, positive action by employers would benefit those with symptoms, and contribute to employee engagement, productivity and retention.

Recommendation 14

I recommend that the Faculty of Occupational Medicine co-ordinates the production of evidence-based guidelines for employers to ensure that they provide appropriate advice and support to women experiencing disabling symptoms while going through the menopause.

Urinary and faecal incontinence affects the lives of over 5 million women in the UK. Poor function of the pelvic floor also allows prolapse of bowel and bladder into and sometimes outside the vagina. Women with incontinence change the way that they dress because of it, and modify their activities and habits so as to always be near to toilet facilities; some simply do not go out – and correspondingly have a reduced quality of life.

Prolapse and incontinence affect women's sex lives and relationships and cost the health service and individuals millions of pounds each year in pads, catheters, medication and other treatments. Six weeks after pregnancy, 33% and 10% of women report urinary and faecal incontinence respectively; 10 years later 20% of all women who have been pregnant still report urinary incontinence and 3% report faecal incontinence. This is morbidity, not mortality, but the number of women affected is enormous. Because these subjects are still taboo, greater public awareness is needed to empower women to access self-help resources and treatment pathways.

Recommendation 15

I recommend that Public Health England convenes a group of stakeholders to consider ways of

- a) raising awareness of urinary and faecal incontinence and prolapse in women, and**
- b) improving signposting to resources, self-help information and treatment pathways which alleviate these conditions.**

Measures to provide services for the increased numbers of women presenting with symptoms which are likely to arise from such a campaign are outlined in Chapter 10. These include direct access to physiotherapy and properly resourced continence nurse services, and these services may represent cost-effective alternatives to GP consultation and referral as initial triage and treatment.

Women and cancer

Chapter 11 Female cancer survival in England

In this chapter, the authors focused on ovarian cancer, for which one-year survival is significantly worse in England than in comparable healthcare systems around the world. They also highlight the rise in uterine cancer, linked with the rise in obesity and discuss the impact of the national screening programme in reducing cervical cancer incidence and mortality and future effects of HPV vaccination.

There is debate as to why ovarian cancer survival is lower in England than in some peer nations. Early diagnosis is difficult for ovarian cancer due to the relatively silent nature of the most common type. At this time there is no evidence that screening for ovarian cancer improves survival but this may change with the publication of the United Kingdom Collaborative Trial of Ovarian Cancer Screening later this year.

Relatively low survival from ovarian cancer in the UK does not appear to be related to more women presenting with advanced stage disease (stage III and IV), but instead to lower stage-specific survival. Patient and treatment factors contribute to this, however the major prognostic factor for advanced ovarian cancer outcome is the extent of cytoreduction (the measurable amount of cancer left) after primary surgery. The time spent operating and the ability to perform advanced surgery are factors in achieving complete cytoreduction. In an international randomised control trial of treatment for advanced stage disease, operating times in the UK were lower than for comparable countries, as were rates of complete cytoreduction and survival, suggesting less effective surgery. Improvement of surgical treatment of advanced-stage disease in England will require development of the training of sub-specialist gynaecological oncology surgeons and of the skills of those in practice. In addition, outcomes of ovarian cancer should be audited nationally, a measure which has improved survival in bowel, head and neck and oesophageal-gastric cancers.

Recommendation 16

I recommend that the Royal College of Obstetricians and Gynaecologists ensures that sub-specialist training in gynaecological oncology equips doctors to perform optimal surgery for gynaecological cancers and reduce mortality from ovarian cancer.

Recommendation 17

I recommend that a national clinical audit should be undertaken of treatment and survival trends for women with ovarian cancer in England. High priority should be given to including this topic in NHS England's National Clinical Audit and Patient Outcomes Programme commissioned by the Healthcare Quality Improvement Partnership.

My annual reports are a key part of my statutory duties as the Chief Medical Officer and provide opportunities to shine a light into areas of missed opportunity as well as to report on the state of the public's health. I really hope the recommendations from this report will lead to action and deliver improvements to the health of women in England and to future generations. My report chapters are commissioned from leading academics and clinicians and I am indebted to the authors who have given their time and expertise, to those who provided advice during the scoping period and to the reviewers of the chapters.

The case stories of women's experiences throughout the report bring the issues discussed at population level into focus by describing their impact on the lives of individuals and I thank the women who have shared their experiences. I also want to thank Clinical Practice Research Datalink for access to data to supplement several of the chapters and I am grateful to the staff and analysts who worked to provide this information.

Chapter 2

Gender-based violence against women

Chapter lead

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Gender-based violence against women

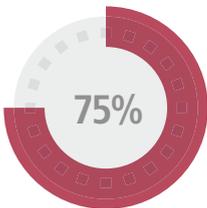
2.2% OF WOMEN IN ENGLAND AND WALES IN 2013–14 EXPERIENCED SEXUAL VIOLENCE

1.5m ADULTS (84% WOMEN) IN ENGLAND AND WALES HAVE A HISTORY OF ABUSE (PHYSICAL AND/OR SEXUAL DATING BACK TO CHILDHOOD)

6,071 WOMEN IN 2012 CAME TO THE UK SEEKING ASYLUM IN THEIR OWN RIGHT

HAD EXPERIENCED RAPE

REPORTED BY

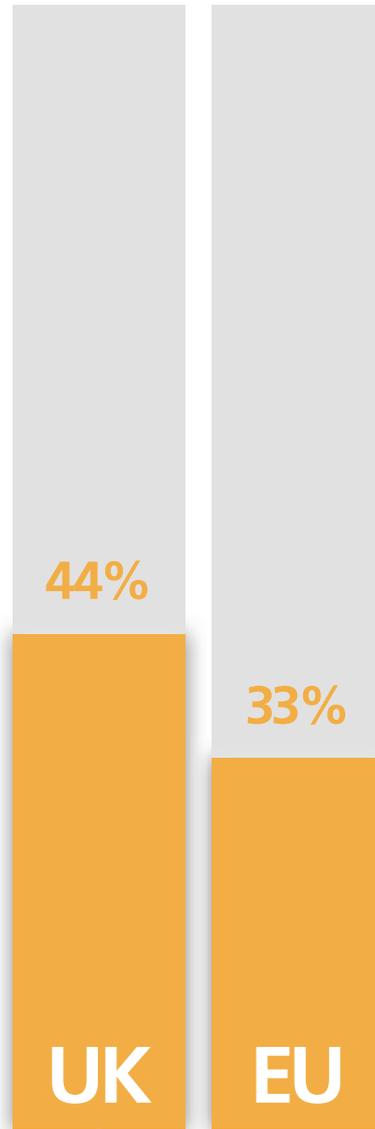


HAD BEEN TORTURED

REPORTED BY



% WOMEN REPORTING PHYSICAL AND/OR SEXUAL VIOLENCE SINCE THE AGE OF 15

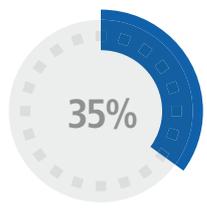


10,000-13,000

(55% WOMEN) POTENTIAL VICTIMS OF MODERN SLAVERY ESTIMATED TO BE IN THE UK

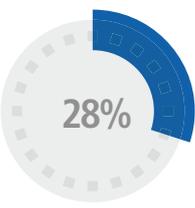
TRAFFICKED FOR SEXUAL EXPLOITATION

REPORTED BY



EUROPEAN VICTIMS ENCOUNTERED HEALTHCARE WORKERS WHILE IN A TRAFFICKING SITUATION

REPORTED BY



1. Key statistics

- The *2013/14 Crime Survey for England and Wales* (CSEW) reported that 2.2% of women and 0.7% of men (aged 16–59) had experienced some form of sexual assault in the past year.
- The *Adult Psychiatric Morbidity Survey in England 2007* estimated that around 1.5 million adults, of whom 84% were women, had experienced extensive physical and sexual violence, with an abuse history extending back to childhood. Over half of these adults had a common mental disorder such as clinical depression or anxiety.
- The *Safeguarding Teenage Intimate Relationships* survey of 4,500 young people aged 14–17 across the UK and four other European countries reported that the highest rates of sexual coercion of teenage girls were in England, and young people were at least twice as likely to have sent a sexual image or text message if they were also experiencing violence or coercive control in their relationships.
- There are estimated to be 80,000 sex workers in the UK, of whom 70% have a history of local authority care and nearly half have a history of childhood sexual abuse. 85–90% of sex workers are women, although the proportion is 60–70% in central London. The Association of Chief Police Officers has estimated that 30,000 women are involved in off-street prostitution in England and Wales.
- The Home Office estimates that there are 10,000–13,000 potential victims of modern slavery in the UK; 55% of these are female and 35% of all victims are trafficked for sexual exploitation.
- Between a half and two-thirds of women prisoners suffer from depression; women prisoners often have histories of domestic violence, sexual abuse and coercion.
- In 2014, Women for Refugee Women published the results of a survey of 46 women who had sought asylum and had been detained; 72% said that they had been raped and 41% said that they had been tortured. A systematic review of asylum seekers' experiences of violence reported greater than 30% exposure to violence, but emphasised the enormous gap in good-quality, policy-relevant information on asylum, violence and health.

2. Overview

Gender-based violence (GBV) violates women's human rights, undermines their ability to participate fully in society and has detrimental consequences for their physical and mental health. It may take a variety of forms, including domestic violence and abuse (DVA), sexual violence, forced marriage, and female genital mutilation (FGM).¹ Rooted in gender inequality and unequal power relations, GBV against women is the result of multiple risk factors. The interconnections between risk factors and how they lead to experiences of GBV and harm can be understood using ecological models. These articulate contextual factors at societal, institutional, community and individual levels.² Hagemann-White's model³ provides a useful framework for developing strategies for prevention because it highlights those factors that are conducive to perpetration and increase vulnerability to GBV and which therefore need to be disrupted to effectively prevent GBV. Preventive measures need to include challenging of gender stereotypes, involve men and boys, address the needs of vulnerable groups and empower women.⁴

This chapter provides an overview of the health impacts of GBV for women and to a lesser extent for adolescents. It is not intended to be a comprehensive overview. As the evidence for prevention and intervention is strongest in relation to DVA, we do not focus specifically on this issue. Instead we focus on forms of GBV, and groups affected, which are not adequately covered in the National Institute for Health and Care Excellence (NICE) Domestic Violence and Abuse guideline [PH50]. While government policies have been developed or are being considered for forms of GBV other than DVA,⁵ there are gaps in pathways for prevention and intervention with regard to sexual violence and so-called 'honour'-based violence (HBV), and in relation to vulnerable groups including sex workers, lesbian, gay and bisexual women, women in prison or detention centres and trafficked women. In this chapter we focus mainly on these issues and groups.

The 2014 NICE DVA public health guideline⁶ provides a strong evidence-based framework for action within health and social care that can also apply to other forms of GBV, with recommendations on commissioning of services, training and care pathways. Implementation of the NICE DVA guideline is at an early stage: most areas do not have integrated commissioning of DVA services nor referral pathways between health services and the DVA sector. Most healthcare professionals still have minimal or no training in DVA. The scope of the NICE DVA public health guideline did not include other forms of GBV, such as sexual violence outside of intimate partnerships or multiple forms of GBV experienced by women, for instance the overlap between domestic and sexual violence, and these are considered in this chapter.

3. Sexual violence

The 2013/14 CSEW reported that 2.2% of women had experienced some form of sexual assault in the past year, mostly less serious sexual assault such as indecent exposure and unwanted sexual touching.⁷ Young women aged 16–19 were most likely to experience sexual assault. A recent European-wide survey of violence against women⁸ reported the UK prevalence of physical and/or sexual violence by a partner or a non-partner since the age of 15 as 44%, compared with 33% across the entire EU. Physical violence in the UK alone was reported as 42% compared with 31% across the EU, with sexual violence in the UK alone reported as 14% compared with 11% in the EU.

Of those (male and female) reporting 'serious sexual assault' in the 2013/14 CSEW, only 17% told the police about the incident. The number of sexual offences (64,205) in 2013/14 was the highest recorded by the police since 2002/03. This probably reflects better recording by the police and a greater willingness of victims to come forward to report such crimes. In addition, publicity surrounding Operation Yewtree is thought to have increased the reporting of historical offences.

Nearly half of victims in the 2013/14 CSEW (45%) reported suffering physical injuries, mostly bruising, from the most recent serious sexual assault incident that they had experienced since age 16, while three in five (61%) suffered mental or emotional problems, and in 9% of incidents the victim attempted suicide as a result.⁷ Research more generally has identified both self-harm and eating disorders as self-reported health impacts of rape.⁹ One US study found women who experienced rape were significantly more likely to experience post-traumatic stress, sexual, eating and/or mood disorders than those who experienced other severe, life-threatening events such as car accidents, physical attacks or robberies.¹⁰ A Swedish study found similarly that adolescent girls experienced acute stress levels as a consequence of rape, compared with other traumatic events such as traffic accidents or attacks by dogs.¹¹

Data from the 2013/14 CSEW show the extensive overlap between sexual and domestic violence: 47% of serious sexual assaults against women were perpetrated by a male partner or ex-partner, while 33% were by someone who was known to them, but not a partner or family member. Only 16% reported that the offender was a stranger.⁸

Analysis of data from the *Adult Psychiatric Morbidity Survey* in England in the *Violence, abuse and mental health in England: Preliminary evidence briefing* found that adults with extensive experience of both physical and sexual violence were the most likely to describe their health as poor or fair.¹² Approximately 1.5 million adults, of whom 84% were women, had experienced extensive physical and sexual violence, with an abuse history extending back to childhood. Over half of these individuals had a common mental disorder

such as clinical depression or anxiety. However, only 10% were receiving counselling or a talking therapy. A study of police data on rape cases indicates that possibly one in four cases reported to the police involve rape in the context of domestic violence, while at least one in three involve women who have experienced historic childhood sexual abuse. These different experiences are likely to require different care pathways.¹³

Case study – Gloria's story

Gloria suffered sexual abuse from her stepfather as a child. She left home when she was 16, and met her ex-husband with whom she had three children.

Gloria describes her ex-husband as controlling. She explains how he measured the length of her clothes, dictating what she could and could not wear; and how he forced her to sleep on the floor at night. Gloria divorced him shortly before their 25th wedding anniversary.

In the months that followed their divorce, Gloria's GP referred her to a domestic violence support service. Gloria began having one-to-one counselling sessions. Though Gloria had received counselling support in the past, she had never revealed the abuse she suffered as a child. For the first time in her life, she found herself able to speak about it.

A year later, Gloria reported her childhood abuse to the police. She was referred to a Sexual Assault Referral Centre and assigned an Independent Sexual Violence Advisor (ISVA). The ISVA helped Gloria manage her sick leave with her employer, organised and accompanied Gloria on court visits, and helped Gloria make decisions about finances. Gloria's stepfather was found guilty of sexual assault and rape, and received fourteen years in prison. Gloria says she could not have gone through the court case without the ISVA's support.

During this time, Gloria also started attending a support group, where she was able to meet people who had suffered similar experiences to her. Gloria says that this was her greatest source of emotional support. However, due to lack of funding, the support group had to shut down.

Gloria's life is a struggle. She has not felt able to resume her counselling sessions. She has cut off most ties with her family and rarely meets friends. She is now back at work, having had a year off sick. However, she feels unsupported by her employer, who, she says, expects her to carry on as if nothing ever happened.

There has been increasing attention on new forms of sexual violence, such as sending sexual images (not always an act of violence) and 'revenge pornography' using social media. Young people's relationships in particular can be open to abuse through social media.¹⁴ The Safeguarding Teenage

Intimate Relationships (STIR) project,¹⁴ surveying 4,500 young people aged 14–17 across the UK, Bulgaria, Cyprus, Italy and Norway, found that young people were more likely to have sent a sexual image or text message if they were experiencing violence or coercive control in their relationships. They were at least twice as likely to have sent a sexual image or text compared with young people who had not experienced such abuses. The highest rates of sexual coercion (ie being pressured or forced to accept sexual touching, sexual intercourse or other sexual activity) were reported by teenage girls in England. While both teenage girls and boys sent sexual images, the girls were likely to report negative impacts, while the boys did not. There is an absence of wider research on the impact of sexual violence via social media, however research on cyber bullying (a term that covers violence and aggression against young people) found such bullying may lead to depressive and suicidal outcomes, with lesbian, gay, bisexual and transgender (LGBT) youth especially vulnerable.¹⁵

4. 'Honour'-based violence

HBV is a crime or incident which has or may have been committed to protect or defend the perceived honour of the family and/or community. HBV tends to be carried out by the victim's family and/or partner and is included within the Government's DVA policy, which includes violence and abuse by partners, (ex)partners and family members. It may involve domestic violence, sexual violence and forced marriage.¹⁶ In 2013 the Forced Marriage Unit provided advice or support relating to individuals from 74 different countries.¹⁷ Women are particularly vulnerable to HBV, and risk for forced marriage appears to be heightened when the individual has learning difficulties, a mental illness or is LGBT.^{17, 18} HBV may involve child marriage, with risk of early pregnancies and attendant health risks, vulnerability to sexually transmitted diseases including HIV/AIDS, and domestic violence. UK studies indicate that forced marriage is often hidden behind other presenting issues, such as eating disorders and self-harm, and may result in suicide attempts.¹⁹

5. Lesbian and bisexual women

It is difficult to provide robust data on the extent of GBV concerning women identifying as LGB, due to the 'hidden' nature of this population. In 2010, data from 1,000 respondents to the CSEW in 2007/08 and 2008/09 who identified as gay, lesbian or bisexual were amalgamated to produce a larger sample.²⁰ With regard to sexual assault, the CSEW found that lesbian women reported the highest prevalence, followed by gay or bisexual men. However, the gender of the perpetrators was not made apparent, nor their relationship to those victimised, and we therefore cannot tell if the lesbians were abused by female partners, former male partners or other men. The *US National Intimate Partner and Sexual Violence Survey* (NISVS) does include data on perpetrators, showing that sexual violence to lesbian and bisexual women was experienced mainly from male perpetrators.²¹ The NISVS found that more than half of bisexual women (57.4%) and a third of lesbian women (33.5%) who experienced rape, physical violence and/or stalking by an intimate partner in their lifetime reported at least one negative impact (eg missed at least one day of school or work, were fearful, were concerned for their safety and/or experienced at least one post-traumatic stress disorder symptom). Living in a context of 'cultural victimisation', associated with homophobia and hate crime, may detrimentally impact lesbian and bisexual women's health and wellbeing, and creates barriers to seeking help.²²

6. Sex work

Of the estimated 80,000 sex workers in the UK, 70% have a history of local authority care and nearly half have a history of childhood sexual abuse.²³ An estimated 85–90% of sex workers are women, although the proportion is 60–70% in central London.²⁴ The Association of Chief Police Officers (ACPO) estimated that 30,000 women are involved in off-street prostitution in England and Wales. ACPO estimated that 17,000 of these were migrants; however, there is no robust data on migrant sex workers.²⁵ Women involved in prostitution are particularly vulnerable to physical and sexual violence from clients and others,^{26, 27} and have a higher mortality rate than the general population.²⁸

Case study – Lisa's story

Lisa is 36 years old. She is currently on probation for hitting an ex-partner, who is also female. Lisa says that this was the only time that she has ever hit a partner.

Lisa suffered from sexual abuse as a child. She was diagnosed with borderline personality disorder in her teenage years and was offered psychiatric support. Though she used the service when she was younger, she found it of little help. Lisa has never been offered support for the sexual abuse she suffered.

In her early twenties, Lisa suffered as a victim of domestic violence. She never sought help, as her partner forbade it. She says she felt very isolated.

Lisa says that being a lesbian has made it harder for her to access health and support services. Lisa was made homeless on one occasion and she recalls how her sexuality made it harder for her to find a place to stay. Lisa also says that she would have benefited from having a local lesbian and gay drop-in centre. The nearest centre was too expensive for her to access, and she felt uncomfortable talking to her GP.

7. Modern slavery

The Home Office estimates that there are between 10,000 and 13,000 potential victims of modern slavery in the UK;²⁹ it further estimates that 55% are female and 35% are trafficked for sexual exploitation. Modern slavery describes offences of human trafficking, forced labour and domestic servitude. The Home Office states that human trafficking is the recruitment and movement of people – often through deception, coercion, and abuse of vulnerability – for the purposes of exploitation.³⁰ Men, women and children are trafficked within the UK and from overseas for a variety of purposes, including forced sex work, domestic servitude, labour (including in construction, agriculture, factories, restaurants, car washing and nail salons) and criminal activities (including growing cannabis, benefit fraud and selling counterfeit goods).

Although there is limited research on the health needs of trafficked people,³¹ we know that they experience numerous health risks prior to, during and following trafficking.³² Although findings are based on only one European survey, 95% of women trafficked for sexual exploitation have experienced physical and sexual violence.³³ Commonly reported physical symptoms include headache, back pain, stomach pain, dental pain, fatigue, dizziness and memory problems.³⁴ There is a high prevalence of post-traumatic stress disorder (PTSD), depression and anxiety among trafficked women in contact with support services, with increased risk if they experienced abuse during trafficking, longer duration of trafficking and poor post-trafficking social support.³⁵ No research has been conducted to date on methods to improve mental health outcomes of trafficked people.

8. Adult women in prison

Women prisoners often have histories of domestic violence and/or sexual abuse, as well as mental illness and addiction that may result from, and increase risk for, such abuse.^{36, 37} A cohort study of prisoners which included a small group of women showed that they were nearly twice as likely to be identified as suffering from depression as male prisoners (65% versus 37%), and more than three times as likely as women in the general population (19%). Those suffering from anxiety and depression are significantly more likely to be reconvicted in the year after release from custody compared with female prisoners without such symptoms, which is not the case for male prisoners.³⁸

9. Women asylum seekers and irregular migrants

In 2012, 6,071 women came to the UK seeking asylum in their own right and 1,902 women who had sought asylum were detained. Many women arrive under a male head of household and may not be given the opportunity to disclose abuse. In a survey of women detained in Yarl's Wood, three-quarters said that they had experienced rape and almost half had been tortured prior to seeking asylum.³⁹ Internationally, migrant women may be at greater risk of reproductive health problems and poor pregnancy outcomes,⁴⁰ not least because of the sexual violence that they have experienced. Asylum seekers with temporary protection tend to have poorer mental health than refugees who have permanent residency.⁴¹ Mental health problems of asylum seekers are amplified by detention, particularly PTSD in survivors of torture.⁴² There is a risk of abuse, including sexual violence, in detention.³⁹ Even in the absence of abuse, surveillance by male guards can be traumatic for women asylum seekers who have experienced sexual violence.³⁹ The deterioration of women's health in detention is exacerbated by poor access to reproductive healthcare and mental health services.²⁶

10. Responses to gender-based violence against women

There is variable evidence for effective responses to GBV. Below we give examples of current interventions and recommendations at individual, community and system levels. The evidence of effectiveness, including cost-effectiveness on outcomes, is strongest for DVA interventions, as articulated in the NICE DVA public health guideline,⁷ although studies do not usually include vulnerable groups. There are recommendations in the NICE guidelines that could be applied to sexual violence and to the vulnerable populations discussed above, until better evidence is available. The most relevant recommendations include creating a safe environment in healthcare settings that encourages disclosure of violence (NICE DVA recommendation 5), asking about violence (NICE DVA recommendation 6), providing referral pathways to specialist GBV services, and including GBV in undergraduate and postgraduate training and continuing professional development (NICE DVA recommendation 17).

The World Health Organization guidelines on responding to intimate partner violence and sexual violence against women⁴³ show the overlap between an appropriate healthcare response to DVA and to sexual violence, with many recommendations in common, including the provision of compassionate, non-judgemental first-line support to patients who have experienced violence, and use of holistic targeted responses. Those guidelines also include specific recommendations to clinicians about caring for women after sexual violence, focusing on the first 5 days after an assault (Section 3.1), including HIV and sexually transmitted infection prophylaxis, emergency contraception and psychological interventions, as well as psychological interventions in the longer term (Section 3.2).

10.1 Sexual violence

In the UK, specialist interventions for victims of sexual violence are provided through Sexual Assault Referral Centres (SARCs), Rape Crisis Centres (RCCs) and Independent Sexual Violence Advisers (ISVAs). Generic mental health services provide intervention, not necessarily involving specialist input.¹⁰ RCCs have an important role in providing counselling for adult survivors of childhood sexual abuse and other victims.²⁹ RCC data indicate that 85% of people accessing services at RCCs do not report to the police, with over 60% of service users seeking support for sexual violence that occurred over two years ago. A large proportion of these are adult survivors of sexual violence experienced in childhood.⁴⁴ Evaluation of sexual violence services in the UK has been minimal, although evaluation of SARCs in the early 2000s was positive.⁴⁵ A wider review of evidence⁴⁶ found: moderate evidence for educational and psycho-educational sexual violence prevention programmes; moderate evidence for rape prevention programmes; and moderate evidence for the benefits of assertiveness and risk reduction training in preventing sexual violence. There is evidence that cognitive-

behavioural therapy (CBT), eye movement desensitisation and reprocessing (EMDR) and psychotherapy can reduce PTSD and associated symptoms. Also, 'Bystander interventions', which aim to shift attitudinal norms and GBV perpetrator behaviour, have shown some effectiveness in involving boys and men in prevention.⁴⁷

10.2 'Honour'-based violence

Practitioners find it difficult to know how to respond to HBV.^{48, 49} Despite HBV constituting abuse, issues of culture and the desire to maintain good community relations may be given priority over intervention in the abuse.⁵⁰ Practitioners working with victims of forced marriage and HBV need to consider the 'one chance' rule. That is, they may only have one opportunity to speak to a potential victim.⁵¹ There are national and some local specialist services providing support for victims of HBV.* However, studies on the effectiveness of such interventions are limited. Southall Black Sisters have developed a 'hybrid' model of psychotherapy for survivors that combines established humanistic, cognitive-behaviourist and psychodynamic therapies, and takes into account the impact of pressures arising from notions of 'shame' and 'honour', and of racism. It appears that this may be effective in reducing PTSD.⁵²

10.3 Sex work

The Home Office 'Ugly Mugs' pilot scheme identified violent clients and shared information in order to prevent further violence against sex workers and to enable reporting. Evaluation found increases in awareness about violence against sex workers and increased likelihood of reporting to the police.⁵³ Drug use is a particular problem for women involved in on-street prostitution, with type of drugs used and their effects having direct implications for interventions, prevention and care pathways.^{27, 54} A review of GBV approaches and services⁴⁶ found no evaluation of prevention responses, identification or referral, and weak evidence that empowering women by involving them in other paid work combined with health education (specifically concerning HIV) reduced risky sexual encounters, increased use of protective prophylactics or reduced drug use.⁵⁵ There was promising evidence on outreach services,⁵⁶ echoing a Home Office evaluation,²⁷ in which outreach to engage sex workers, combined with one-to-one work and fast-track drug services within a holistic approach geared to individual needs, allowed women and young people to become more stable, to stay healthy and to have opportunities to leave sex work. These services have been established in several UK cities, including London⁵⁷ and Bristol.⁵⁸ Interventions should be proactive regarding mental health (ie psychological distress, post-trauma reactions and diagnosable illnesses) and healthcare professionals should receive training about the specific needs of sex workers and their related health problems. General practitioners, emergency department clinicians and mental health professionals should know about referral pathways

and specialist support services, as encounters with these professionals may provide the opportunity for sex workers to have access to various types of support.⁵⁹

10.4 Modern slavery

Trafficked people experience a range of health risks prior to, during and following their trafficking experiences,²³ but there is no research on effectiveness of psychological, social or welfare interventions to support psychological wellbeing and recovery. Within health services, it would be beneficial if clinicians were aware of the signs of trafficking among patients and aware of the availability of the UK national helpline.[†] A study of the experiences of European victims of trafficking found that 28% encountered healthcare providers while they were in the trafficking situation; unfortunately all opportunities for intervention were missed.²⁵ A medical student project entitled *Can modern medicine do anything for modern day slavery?* is making the case for inclusion of trafficking into the undergraduate curriculum,⁶⁰ and developing training materials.⁶¹

10.5 Prison

The complex needs of women prisoners resulting from previous domestic abuse and sexual violence, mental health and addiction problems, requires holistic, personalised support. Such an approach could be cost-saving, and possibly more so if delivered to adolescents.⁶² The possible link between women's experiences of domestic and sexual violence and abuse and their offending behaviour should be taken into account when designing local service provision for women victims and offenders. Co-ordinated services bringing together police, health, women's services and local authorities to provide tailored support, such as with the Hull Women's Triage Pathfinder Project, have begun to show evidence of positive impact, with fewer women being charged and very low re-offending rates.³⁷

10.6 Women asylum seekers and irregular migrants

With regards to GBV experienced by women asylum seekers or irregular migrants, there is a strong moral and health-based case for not detaining women who have experienced rape, sexual violence and other forms of torture. Specifically, asylum seekers who have been abused have high prevalence of mental health problems, which is likely to be exacerbated by detention and the inadequate mental health services available for detainees. Women who are registered under a male head of household should be given an opportunity to report current or past abuse and be supported in referral and access to SARCs. Detention and dispersal of pregnant asylum seekers and irregular migrants who have committed no crime has the potential to damage the health of mother and fetus.⁶³

* *Forced Marriage Unit* 020 7008 0151, *Karma Nirvana* 0800 5999 247, *Southall Black Sisters* 020 8571 0800

† *Modern Slavery Helpline* 0300 303 8151 (phone the police on 999 for emergencies)

11. Authors' suggestions for policy

- Gaps in healthcare professional GBV training could be addressed. For instance, information about modern slavery could be included in undergraduate and relevant (ie general practice, obstetrics and emergency medicine) postgraduate training and the Modern Slavery Helpline could be more prominently displayed in healthcare settings.
- GBV requires professionals to provide compassionate, non-judgemental first-line support. Use of holistic, targeted responses that include specialist support is appropriate as a general approach.
- GBV prevention policy could include initiatives that challenge gender stereotypes, involve men and boys, address the needs of vulnerable groups and empower women through holistic support and economic inclusion.
- The NICE 2014 DVA guideline could be used as a starting point to develop integrated commissioning of GBV services and supported referral pathways between health services and the GBV sector, taking into account the overlaps between different experiences of GBV, specific needs of different victims/survivors and their needs at individual, community and system levels. These services and pathways should ensure inclusion of marginalised groups; inclusion means proactive and outreach access to these services, as well as programmes within those services that address the specific needs of these groups.
- The implementation of the NICE DVA guideline should be monitored, particularly with regard to local integrated cross-sectoral commissioning strategies and referral pathways between healthcare and specialist GBV services. Adequate funding is required in order to maintain services shown to be cost-effective.⁶⁴
- Commission specialist sexual violence services in all areas to link with SARCs.
- The authors of this chapter are of the opinion that it is inadvisable to detain those asylum seekers and irregular migrants who have experienced rape, sexual violence or other forms of torture, and those who are pregnant.

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Chapter 3

Female genital mutilation (FGM)

Chapter lead

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Female genital mutilation (FGM)

In 2014 the World Health Organization estimated that there are **125 MILLION** women and girls worldwide who have survived FGM

127,000

ESTIMATED NUMBER OF **WOMEN AND GIRLS** (AGED 15-49) WHO ARE SURVIVORS OF FGM LIVING IN ENGLAND AND WALES

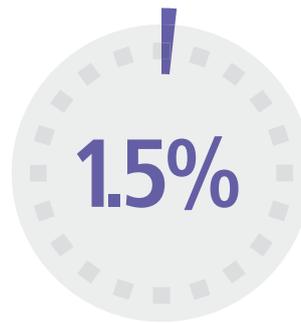
60,000

ESTIMATED NUMBER OF **GIRLS BORN TO MOTHERS** WITH FGM (ENGLAND AND WALES)

Long-term health issues of FGM include

Scarring
 Post-partum haemorrhage
Painful sex Embarrassment
 Perinatal death **FGM**
 Post Traumatic Stress Disorder
 Reduced sexual satisfaction
 Urinary tract infections

Depression
 Anxiety



ESTIMATED PERCENTAGE OF **WOMEN GIVING BIRTH** IN IN ENGLAND AND WALES EACH YEAR WHO ARE SURVIVORS OF FGM

1. Key statistics

- In 2011, researchers at City University London estimated that there were circa 127,000 adult survivors of FGM living in England and Wales.
- In 2011, researchers at City University London estimated that there were 60,000 girls under 15 living in England and Wales who were born to mothers with FGM.
- In 2014, the World Health Organization (WHO) estimated that more than 125 million women worldwide are living with the consequences of FGM.
- In 2014, the WHO stated that, globally, the trend towards 'medicalisation' was increasing, with more than 18% of all FGM performed by healthcare providers.
- In 2011, researchers at City University London estimated that, since 2008, women with FGM have made up about 1.5 per cent of all women giving birth in England and Wales each year.
- Of the 14 FGM clinics listed on the NHS England and NHS Choices websites, 9 are in London.

2. Introduction

In July 2014, the Public Health Minister for England announced the launch of the Department of Health and NHS England FGM Prevention Programme. The programme of work focuses on prevention and care, with the ultimate aim being to get a better response to FGM from the health services.¹ The programme was welcomed by activists, community groups and health professionals who have campaigned in the UK since the practice of performing FGM became illegal in 1985. Health professionals, especially in obstetrics and gynaecology, have seen increasing numbers of women from FGM-practising communities. A key aspect of the programme has been the collection and publication of monthly figures from the Health and Social Care Information Centre (HSCIC) of the numbers of cases of FGM reported by health professionals.² These data are essential for service planning and prevention strategies (see Table 3.1).

The figures, however, have been misinterpreted. For example, the former Minister of State for Crime Prevention said in an interview that with recording from acute trusts, '...we now know that there have been 2,000 cases of FGM in England and Wales'.³ This could suggest that FGM is performed in the UK and that trained health professionals are ignoring it or are ineffective at identifying cases for prosecution. It is vital to understand that the majority of cases included in current prevalence data are not new but are women who have undergone FGM in childhood outside the UK. Women with FGM tend to present to health professionals either with symptoms such as inability to have sex or during investigations for an unrelated condition, including pregnancy.

Table 3.1 Number of FGM cases reported by acute trusts in England to the Department of Health, September to December 2014

	Sept	Oct	Nov	Dec
Newly identified cases*	467	455	466	558
Active cases**	1,279	1,468	1,803	2,146
% of eligible trusts reporting data	78%	69%	79%	83%

* Patients first identified during the reporting period as having undergone FGM.

** Patients identified as having a history of any FGM type prior to the reporting period and still being actively seen/treated for FGM-related conditions or any other non-related condition at the end of the month. This does not include newly identified patients.

Data collection is essential, as the risk for girls living within the diaspora communities is real, but remains unquantified. Indicators for the practice continuing in the UK have not been studied. Data collection has been introduced rapidly as part of other requirements for health professionals and it will take time for all health professionals to be educated in the recognition of FGM and the importance of data collection. Given current misconceptions surrounding this data, there is a need to ensure appropriate care for FGM survivors and a sensible approach to prevention. This may be aided by doctors understanding the health impacts of FGM in the UK population, their own responsibilities for reporting and recording FGM, and the methodology of FGM data collection and the implications of published figures.

3. What is FGM?

FGM is a tradition practised in some, but not all, countries in Africa, Asia and the Middle East. Although no religious scripts prescribe FGM, practitioners often believe that the practice has religious support. In most societies where it is performed, FGM is considered a cultural tradition and this is often used as an argument for its continuation. FGM (also known as circumcision or cutting) is almost always performed on children and estimates suggest that more than 125 million girls and women worldwide are living with the consequences.⁴ It is defined as 'all procedures that involve partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons' (see Table 3.2).⁴ There is wide misperception about the social benefits for the community.^{5,6} FGM has no health benefits and can cause serious damage to the physical and psychological health of women and girls.

Patterns are changing, with reported increased use in some countries of health providers in order to perform 'medicalised FGM'. Previously FGM was most commonly performed by traditional cutters on individual, or groups of, children, often at a celebration without anaesthetic or sterile conditions. The child is restrained while the external genitalia are cut/removed and/or stitched with a knife, scalpel or other sharp tool. In Egypt, where 91% of girls undergo FGM, 77% of cases were reported to have been performed by a trained medical practitioner (most commonly a doctor).⁵ WHO figures suggest that over 18% of FGM is performed by health providers.⁴

Table 3.2 WHO classification of FGM

Type 1	Clitoridectomy: Partial or total removal of the clitoris (a small, sensitive and erectile part of the female genitals) and in rare cases only the prepuce (the fold of skin surrounding the clitoris).
Type 2	Excision: Partial or total removal of the clitoris and labia minora with or without removal of the labia majora (the labia are the 'lips' that surround the vagina).
Type 3	Infibulation: Narrowing of the vaginal opening through the creation of a covering seal. The seal is formed by cutting and repositioning the labia minora or majora with or without removal of the clitoris.
Type 4	Other: All other harmful procedures to the genitals for non-medical reasons, eg pricking, piercing, incision, scraping and cauterising the genital area.

4. Prevalence

4.1 Estimated prevalence data

There is little information on FGM among communities relocated to high-income countries. Office for National Statistics figures have been used to derive prevalence estimates from numbers of migrants born in countries where FGM is practised and where rates of FGM are known. In 2011, there were an estimated 127,000 survivors of FGM in England and Wales.⁷ In addition, 60,000 girls under 15 were estimated to be born to women with FGM.⁸ While some studies suggest a decline in FGM,⁹ other sources suggest that it continues but with some differences in age and type.⁵

4.2 Measured data

Acute trusts within the NHS are now required to collect data on patients seen with FGM² and this requirement has recently been extended to general practice and mental health trusts. With no extra funding, trusts must make their own internal arrangements for data collection. The quality of the data is currently variable but data collection could become more accurate thanks to a background of increasing FGM awareness and education. As yet, it is too early to analyse patterns of FGM but possible uses include identification of 'hotspots' of FGM for targeting clinical services and prevention work and to identify potential mismatches in areas where prevalence is expected to be high but is reported to be low.

5. Research data on health implications

There is little robust evidence on the health impact of FGM. Most population-based studies are retrospective, relying on women's recollections of their past FGM. Women know that they have had FGM but may not always know exactly what has been done¹⁰ and studies have not included girls who die due to the procedure. Women may be unwilling to disclose symptoms due to the sensitive nature of the subject, or because FGM symptoms such as urinary obstruction may be so chronic that women assume that these are normal, or because of the legal status of the practice. This may include not bringing their daughters, who had FGM before they entered the UK, to a consultation with a health professional for fear of the legal consequences, which may lead to delays in medical care.

6. Trends

International research has identified that the age at which FGM is being performed has remained fairly stable. Where change has occurred, the most common trend is to perform FGM at a younger age,⁵ which ensures less objection or disclosure.⁵ Type 4 FGM, where a small cut or prick is made on or lateral to the clitoris, is more common, known by some communities as 'Sunna'. This causes little tissue damage and little or no scarring, so may be impossible to distinguish confidently from tiny irregularities due to congenital variation. This trend towards medicalised type 4 FGM has been confirmed in a series of 27 girls under the age of 18 seen in the only UK clinic for children with FGM.¹¹

Case study – Armana's story

Armana was born in Eritrea. She underwent infibulation when she was two months old, as is normal for all girls in her tribe.

Armana says she felt pain from it for most of her life. She says it hurt to pass urine and have periods; and it hurt to sit down for any long period of time, to run up the stairs and play sports with her friends.

The customs of Armana's tribe mean that, at thirteen years old, girls have to marry or become soldiers. Armana's parents feared for their daughter, and they helped Armana run away. Armana travelled by herself to Sudan, and then took a boat to Europe. After many months of travelling, she arrived in the UK.

Armana now lives with a foster family in England. With the help of her foster mother, she has been able to undergo a de-infibulation operation. Armana says she feels much happier now: she says she can pass urine and have periods without pain; she can sit in her lessons without having to get up; and she can play football with the rest of her classmates.

Armana wants to encourage more girls who have undergone FGM to seek help. She says that even though it was hard, it was worth it, because she feels so much happier as a result.

7. Health implications

7.1 Immediate effects

All reports on immediate complications of FGM come from Africa and there are no reports from England. Possible explanations for this may be that children are sent abroad for FGM and do not return to the UK until recovered, or a trend towards less invasive forms of FGM (ie type 4) with fewer complications. Immediate effects include haemorrhage and infection, including wound infection, septicaemia, tetanus and gangrene.¹² Although deaths have been reported, actual rates are unknown. Infection may occur due to the use of shared and unsterile tools and may include the transmission of blood-borne infections (eg HIV, hepatitis B and C and syphilis), although some of these infections are endemic where FGM is prevalent. Damage to adjacent organs such as the urethra may occur during FGM.

7.2 Longer-term health issues

FGM can cause obstetric, gynaecological and psychological problems. Obstetric outcomes for mother and baby include increased rates of post-partum haemorrhage, perineal trauma and perinatal death.¹³ Obstetric interventions can reduce some adverse impacts.¹⁴ Gynaecological conditions include genital scarring, keloid and clitoral cysts and recurrent urinary tract infections.¹⁵ Embarrassment can prevent women from seeking routine screening, such as cervical smear tests.¹⁶ FGM can damage sexual function by narrowing the vagina, making sex difficult or painful and by removal of the clitoris and other sensitive sexual tissue, leading to reduction of sensation and pleasure. A systematic review and meta-analysis of studies from Africa, Saudi Arabia and Israel found that women with FGM were more likely to report dyspareunia, absence of sexual desire and reduced sexual satisfaction.¹⁷ Mental health problems such as anxiety and depression have been linked to FGM. A small study from Senegal suggested that FGM can also be associated with Post-Traumatic Stress Disorder (PTSD) although this finding needs further evaluation before applying it to other groups.^{18, 19}

8. Clinical management

8.1 FGM in pregnancy

It is mandatory that all pregnant women, irrespective of country of origin, should be asked about FGM. Referral to an obstetrician or midwife with responsibility for FGM allows a genital inspection to determine the type of FGM. A de-infibulation procedure may be required in women found to have type 3 FGM, where the vaginal opening is obscured by scar tissue. It is usually recommended that de-infibulation is performed in the second trimester, although this is due to concern that staff may not be familiar with de-infibulation rather than because of any medical benefit. Women themselves often express a preference to be de-infibulated during labour, as would be customary in their country of origin.

Re-infibulation (closure of the vagina after delivery in order to render intercourse difficult) is sometimes requested by the woman but should not be performed; re-infibulation is illegal as defined by the Female Genital Mutilation Act 2003. This was the basis of the recent (2015) prosecution of two men, who were acquitted. WHO guidelines recommend permanent de-infibulation and include re-infibulation under the definition of type 3 FGM, but do not state that it would be unlawful.⁴ Women with FGM are at increased risk of perineal trauma, including labial tears which may require suturing.¹⁴

The recent (2015) acquittal of a junior obstetric trainee charged with FGM has left doctors and midwives unsure of what may be done to the vulva.²⁰ This case is likely to mean that the post-delivery management of women with FGM will be different to those without FGM, as staff may be reluctant to suture vulval tears in such women, even if medically indicated.

8.2 Reconstructive surgery

De-infibulation

FGM cannot be 'reversed', as surgery cannot restore absent tissue or reduce scarring. However, surgery may relieve some of the physical symptoms. The most frequently performed procedure is a de-infibulation in type 3 FGM, where scar tissue obscuring the vaginal opening is divided. This is a minor surgical procedure usually performed under local anaesthetic in both pregnant and non-pregnant women. While there are no reported studies of the benefits of de-infibulation, it is likely to facilitate labour management and reduce perineal trauma. It also allows painless penetrative vaginal intercourse and relieves the outflow of urine and menstrual blood. Genital surgery may be required to remove large, uncomfortable and unsightly clitoral cysts which can develop following FGM.

Clitoral reconstruction

A recent report claims that reconstructive surgery to the clitoris seems to be associated with reduced pain and restored pleasure.²¹ Current studies are of poor quality, with the majority of patients lost to follow-up and no methodical psychosexual assessment.²² Nonetheless, increasing numbers of women are seeking out clitoral reconstruction. Excised clitoral tissue cannot be restored and further surgery may lead to more scarring and sensation loss. However it is possible that reconstruction as a cosmetic procedure to restore appearance may have some positive psychological benefits. Requests for clitoral reconstruction should be approached with caution until high-quality research is available.

8.3 Mental health services

Complex PTSD is an anxiety disorder caused by very stressful, frightening or distressing events and has been associated with FGM.¹⁹ It requires specialist interventions, which may include medication. Psychosexual problems are likely to require multidisciplinary management. Family difficulties require appropriate input from practitioners in family and children's services.

Some women and girls may benefit from psychological intervention and peer support groups. These should be evaluated in survivors of FGM. At present, there is little training for existing mental health care professionals to offer help to girls and women with specific needs arising from FGM.

9. Services

Existing services have developed historically because of the commitment of an individual health professional determined to improve care for their local population. Of the 14 clinics listed on the NHS England and NHS Choices websites, 9 are in London. Clinics are limited in the populations they serve, as those based within maternity often only see pregnant women and there is only one clinic in the UK for children, based in London. However, new prevalence data should allow local service planning.

The Department of Health (DH) has recently published specifications for commissioning services to support women and girls with FGM.²³ The new specifications include recommendations for service provision in both high and low prevalence areas in England. Each trust should have a designated FGM health professional and a clear referral pathway to a specialist FGM clinic, which may be in another hospital depending on patterns of migration and need. FGM has physical and psychological consequences and services must therefore be multi-disciplinary. Women with FGM most commonly present to women's health services and so services should include an obstetrician/gynaecologist and access to de-infibulation should be available if required.^{24,25} Children with FGM should be seen by or with a paediatrician with relevant expertise and experience, as well as knowledge of safeguarding.²⁶

10. New requirements for recording and reporting

10.1 Recording

Recording is based on clinical history alone. A genital examination is not essential although this does enable the type of FGM to be identified and the woman advised accordingly. FGM should be documented in the patient's notes as would be consistent with good clinical practice and Royal College of Obstetricians and Gynaecologists (RCOG) guidance.²⁵ From April 2014, acute trusts have been required to submit monthly anonymous data to DH. From April 2015, it has become mandatory to submit the DH enhanced dataset, which contains patient identifiers. This dataset includes more detail; genital piercings of any kind are included under type 4 FGM.² Women should be informed that these data are collected and disclosed to the HSCIC.²⁵ Concerns have been raised about confidentiality and it is likely that some services such as sexual health services will be exempt from returning identifiable FGM data on adult women, given their legal obligations regarding confidentiality.

10.2 Reporting

Reporting refers to informing social services and/or the police about a child or woman with FGM. It is already the responsibility of all health professionals (including doctors) to refer a child with or at risk of FGM; this is clearly outlined in national guidance.²⁷ Mandatory reporting to the police of all under-18s found to have confirmed FGM was included in the Serious Crime Bill and is now law. If an under-18 is suspected but not confirmed to have FGM, a referral should be made to a social services duty team, now usually the MASH (multi-agency safeguarding hub). Sanctions – currently unspecified but which might include referral to a regulatory body – will be applied to clinicians for failure to report. This change in the law comes at a time when teaching materials for health professionals on detection and management of FGM in children have only recently become available.^{28,29,30}

Mandatory reporting does not apply to women over the age of 18. If a woman is found to have FGM, health professionals must assess the risk of FGM to other family members. In the case of a pregnant woman, the risk assessment should be part of maternity care, including informing her GP and writing in the baby's red book at birth. In March 2015, DH published guidance for professionals on FGM risk and safeguarding.³¹ This document includes a risk assessment framework tool and specific advice on documentation and information sharing.

10.3 Education

The undergraduate medical syllabus for most medical schools, and the RCOG recommendations for the undergraduate core curriculum, do not include FGM. FGM has been included in the RCOG postgraduate syllabus since 2007, although the module can be completed without seeing an affected woman. The Royal College of Paediatrics and Child Health intercollegiate guidance includes FGM at all levels of child protection training. Health Education England (HEE) has launched an open-access introductory e-learning module on FGM³⁰ as part of the FGM Prevention Programme. Further modules on more complex aspects of FGM were released in March 2015.³⁰ Multi-agency Practice Guidelines²⁷ and the NHS Choices website³¹ have further information.

11. Conclusions

FGM has an impact on the practice of all doctors working within the NHS. New requirements for recording and reporting FGM need to be underpinned by the appropriate knowledge and skills. However, it is important that the intense political pressure on doctors to record and report FGM does not lead to alienation of patients with FGM, as this will isolate the very group of women and girls that they seek to protect. Doctors will need to seek out available resources as part of their compulsory continuing professional development. The new HEE FGM e-learning modules provide comprehensive information, although are not currently mandatory. Emerging prevalence data is crucial to the development of specific local healthcare services for survivors of FGM and targeting of educational work within communities.

Groups from within FGM-practising communities have worked tirelessly for many years to protect girls against FGM, along with many charities. The largest such charity in the UK, FORWARD,³² works to safeguard girls at risk and support affected women by direct community engagement, advocacy and strategic partnerships. Initiatives include training, community programmes and education in schools for teachers, pupils and parents. Each local children's safeguarding board should include the voluntary sector/ community groups in its local multi-agency programme to end FGM, as this is a crucial inroad to grassroots activists and other influential local groups. It is essential that new initiatives do not sideline community groups. Without their involvement, progress cannot be made in preventing FGM and there is a risk that if communities become stigmatised, then the practice may go underground. Links between acute services and the community can be fragile and difficult to maintain.

12. Authors' key messages for policy

- Consider how best to commission multi-disciplinary services for women and girls with FGM in high-prevalence areas, and with clear pathways for referral from low-prevalence areas.
- Priority research areas include:
 - exploration of changing attitudes to FGM in diaspora community groups
 - defining the most appropriate timing of de-infibulation in pregnancy
 - carrying out scientific evaluation of the benefits of clitoral reconstruction in women who have undergone FGM.
- The authors of this chapter suggest that psychology interventions should be evaluated for woman and girls with FGM; the HEE introductory e-learning module ('E-learning to improve awareness and understanding of FGM') should be mandatory for all NHS staff (clinical and non-clinical).
- The authors of this chapter suggest that all under-18s with suspected or confirmed FGM should be seen by or with a paediatrician with relevant expertise and experience, as well as knowledge of safeguarding.

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Post-completion of this chapter, a final report was published in 2015. This includes tables of data for England and Wales separately and for every local authority area:

Macfarlane A, Dorkenoo E. *Prevalence of Female Genital Mutilation in England and Wales: National and local estimates*. London: City University London and Equality Now, 2015. <http://openaccess.city.ac.uk/12382/>

Chapter 4

Eating disorders

Chapter lead

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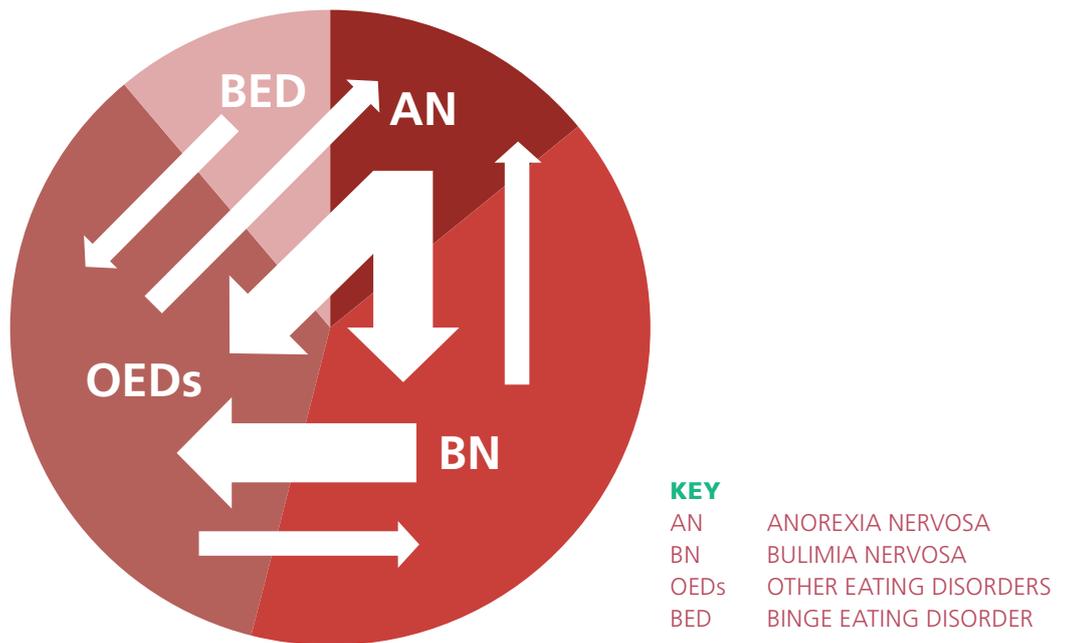
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Eating disorders

Eating disorders have overlapping aetiologies and common treatments

WOMEN HAVE A HIGHER LIFETIME PREVALENCE THAN MEN

DIAGNOSTIC MIGRATION BETWEEN EATING DISORDERS*



* Proportions are amalgamations of differing studies and so are approximated

Treatment



EARLY ACCESS
INCREASES THE
CHANCE OF RECOVERY



EVIDENCE-BASED THERAPY
<18 YEARS: FAMILY BASED THERAPY
>18 YEARS: ENHANCED COGNITIVE
BEHAVIOURAL THERAPY

1. Key statistics

- In February 2015, *The Costs of Eating Disorders — Social, Health and Economic Impacts* estimated that more than 725,000 people in the UK are affected by an eating disorder.
- The National Institute of Health and Clinical Excellence estimates around 89% of those affected by an eating disorder are female.
- NHS Choices estimates that
 - anorexia nervosa affects around 1 in 250 women and 1 in 2,000 (it usually develops around the age of 16 or 17)
 - bulimia nervosa is around two to three times more common than anorexia nervosa, and 90% of people with the condition are female (it usually develops around the age of 18 or 19)
 - binge eating affects males and females equally, and affects around 5% of the adult population (it usually develops later in life, between the ages of 30 and 40)

2. Introduction

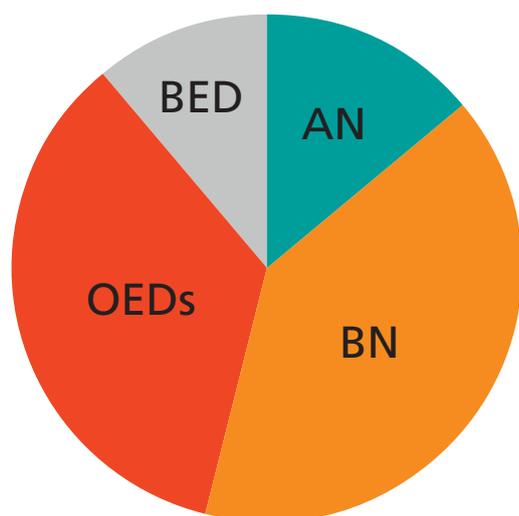
The eating disorders are a group of mental health problems in which a persistent disturbance of eating is the most prominent feature. In the past they were equated with anorexia nervosa (AN), a view that made sense until the late 1970s when bulimia nervosa (BN) was recognised¹ and was found to be much more common. The picture changed again in the 2000s when recognition was given to a form of overeating long known to be associated with obesity,² now termed binge eating disorder (BED).³ At much the same time, it was realised that even more common than BN and BED were 'atypical' states in which the features of AN and BN are combined in other ways.⁴ (There is no consensus on how best to denote these states and the terminology has changed at intervals. In this chapter we refer to them as the 'other eating disorders' or the OEDs.) With this proliferation of eating disorder diagnoses, it is easy to overlook the important fact that the eating disorders other than BED (ie AN, BN and the OEDs) have much in common. Indeed, there are more similarities than differences. This crucial point has important implications for their understanding and management.

3. Eating disorders and their management

3.1 Clinical features

Figure 4.1 shows the typical distribution of the four eating disorder diagnoses among adult outpatients.⁴ The OEDs are the most common diagnosis, followed by BN and then AN. Eating disorder services see relatively few cases of BED. Among adolescents, the diagnostic distribution differs (ie that AN is more common than BN), but the OEDs remain the most common diagnosis.⁵ BED is not often seen in this age group.⁵ AN, BN and the OEDs mainly affect girls or young women: about one in ten patients is male.³ In contrast, men constitute about a third of patients with BED. A typical distribution of the eating disorder diagnoses among adult outpatients⁶ is shown here (Figure 4.1).

Figure 4.1 Typical distribution of the eating disorder diagnoses among adult outpatients in England



Source Christopher G. Fairburn, Professor of Psychiatry, University of Oxford

3.2 Anorexia nervosa

AN typically starts in early to mid-adolescence with a period of dieting that gets out of control and becomes persistent, inflexible and extreme.³ Progressive weight loss results and is accompanied by over-concern about body shape and weight, although this may not be acknowledged and may be absent at the outset. There is a fear of weight gain and fatness, and this drives further dieting. The dieting may be accompanied by other forms of weight-control behaviour including over-exercising, self-induced vomiting and laxative misuse. Typically, sufferers do not acknowledge having a problem; their low weight and extreme weight-control behaviour are consistent with their desire to maintain strict control over their eating, shape and weight.

The course of AN varies greatly. It may be self-limiting; it may require some form of intervention; or it may prove treatment-resistant and persist for many years.^{7,8,9} It can be life-threatening. For those with longstanding AN the outlook becomes increasingly poor over time, although recovery can still occur.¹⁰ In the early years, it is common for AN to evolve into BN or an OED.

3.3 Bulimia nervosa

BN generally starts in late adolescence or early adulthood. It begins in much the same way as AN, but after some months or years the dieting becomes punctuated by repeated episodes of binge eating with the result that any weight lost tends to be regained. ('Binges' are episodes of eating in which large amounts of food are consumed and there is a sense of loss of control at the time.) The binges are often followed by self-induced vomiting or laxative misuse in an attempt to minimise the amount of food absorbed.

Once fully developed, BN tends to be self-perpetuating. It may persist for years or even decades with adverse effects on self-esteem, career and relationships. It is common for sufferers to delay seeking help due to the shame associated with binge eating,¹¹ and it is easy for them to keep the problem secret as their weight is generally unremarkable.

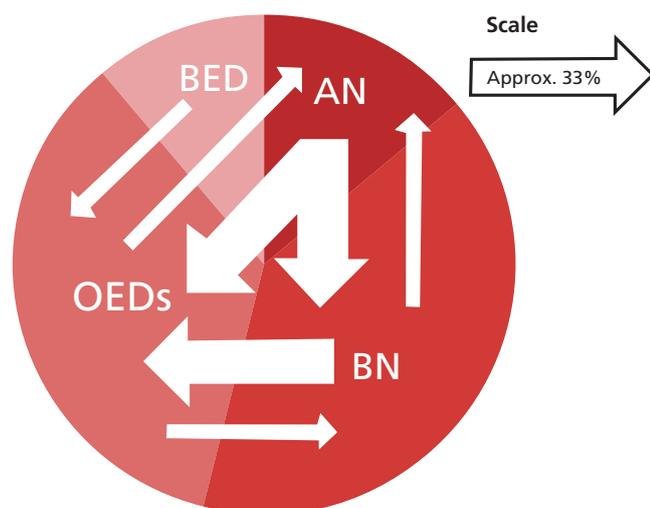
3.4 Other eating disorders

Most OEDs are very similar to AN and BN.^{12,13} There is the same over-concern about eating, shape and weight, and the same tendency to engage in persistent and extreme dieting and other forms of weight-control behaviour. Most of the OEDs are mixed states in which the features of AN and BN are combined in such a way that it is not possible to make either diagnosis. Body weight may be low if the dietary restriction is marked.

Many people with an OED have a history of AN or BN, or both, reflecting the diagnostic migration that is common among the eating disorders^{9,14} (see Figure 4.2, informed by Fairburn and Harrison¹⁵). The OEDs are as impairing as BN: the level of eating disorder features is the same, as is their duration and their impact on everyday functioning.¹²

One small subgroup also merits mentioning. Services specialising in the treatment of young children and adolescents with eating problems see some patients who restrict their eating but not in an attempt to modify their shape or weight. These states vary in nature and have not been well characterised. They have recently been termed 'avoidant/restrictive food intake disorder'.³ Estimates of their prevalence in specialist clinics for children range from 1.5% to 14%.^{16,17} In our experience, they are rarely seen in adults.

Figure 4.2 A schematic representation of the diagnostic 'migration' that characterises the eating disorders



Source Christopher G. Fairburn, Professor of Psychiatry, University of Oxford

3.5 Binge eating disorder

BED differs from the other eating disorders. Unlike AN, BN and the OEDs, there is no tendency to engage in persistent dieting and no over-concern about eating, shape and weight. Rather, there are recurrent bouts of uncontrolled overeating that occur against a background of a general tendency to overeat, much as in many cases of obesity. Indeed, many people with BED are overweight or have obesity.¹⁸ The demographic distribution of BED is also distinctive in that the majority of patients are middle-aged and, as mentioned above, about a third are male.^{18, 19} The course of BED is also quite different.⁹ Rather than being persistent, it is generally phasic with extended periods, often lasting many months, free from the eating disorder.

4. Co-morbidity and mortality

Eating disorders rarely exist in isolation. Most sufferers have accompanying depressive and anxiety features and these may be sufficiently severe to be viewed as co-morbid conditions. A subgroup engages in self-harm and substance misuse.³ Physical complications develop in those who are very underweight and those who engage in extreme weight-control behaviour such as frequent self-induced vomiting.^{20, 21} The mortality rate is raised compared with that expected, allowing for age and gender.²² In AN the risk of death from all causes is increased six-fold and in BN it is doubled. Most deaths in AN are attributable to the physical consequences of the disorder but one in five is due to suicide.

5. Distribution and determinants

In a meta-analysis of eating disorder epidemiology, which included studies from the US, Australia and Scandinavia, the lifetime prevalence of AN was about 0.5%–1.0% in women and <0.5% in men; that of BN was about 0.5%–3.0% in women and 0.5% in men; the World Health Organization (WHO) world mental health survey estimated the prevalence of BED was about 3.5% in women and 2.0% in men.^{23, 24} Among women aged 16 to 35 years, the point prevalence of BN is between 1% and 2% and that of the OEDs as high as 5%.

Incidence of eating disorders in the UK increased from 2000 to 2009;²³ however, this may be due to greater help-seeking, better detection and changes in diagnostic practice.^{23, 25}

The aetiology of the eating disorders is poorly understood. A variety of risk factors have been identified but how they operate and interact is not known.^{15, 26, 27, 28} The most prominent general risk factors for AN and BN are being young and female, and living in a 'Western' culture in which slimness is prized and dieting is common. Even in the relatively homogeneous environment of England, those with an Asian background appear to be under-represented in referrals to eating disorder clinics, although this could be the result of referral bias rather than a lower prevalence rate.^{29, 30} The personality traits of perfectionism and low self-esteem also appear to increase the risk of AN and BN, as does a family history of depression or an eating disorder. In common with many psychiatric disorders, adverse childhood experiences are also associated with an increase in risk. A family history of substance misuse or obesity specifically increases the risk of binge eating as does an early menarche and a history of impulsivity. Family genetic studies indicate that there is an important genetic contribution²⁸ and there appears to be cross-transmission between AN, BN and the OEDs suggesting shared familial liability;³¹ that is, there is heightened vulnerability to developing an eating disorder but not a particular eating disorder. The molecular genetic studies have yielded inconsistent findings, probably in part because of small sample sizes and problems in selecting and defining the phenotypes of interest.²⁸

6. Help-seeking and detection

Many people with an eating disorder do not seek treatment.^{24, 32, 33} Those with AN may not be fully aware that they have a problem or they may attempt to hide it. Those with BN often keep their problem secret. Delays of five years or more between onset and presentation are common, during which time functioning often becomes increasingly impaired.

When people do present for treatment they do so tentatively. Typically, patients with AN come at the insistence of concerned others whereas those with BN or an OED attend of their accord, although they may present indirectly complaining of features associated with the disorder such as depression, menstrual problems or gastrointestinal disturbance.³⁴ Under these circumstances, making the correct diagnosis may not be straightforward. The attitude of the clinician during these appointments is of great importance,³⁵ not least because patients can be easily put off from pursuing further treatment.

6.1 Management

Some eating disorders can be managed in primary care. This is true of many cases of BED and the simpler cases of BN and the OEDs, but the majority of patients require more specialised help. This can generally take place on an outpatient basis.

A small proportion of cases require hospitalisation at some stage, most of whom have AN. This is needed for those who require medical complications to be addressed or weight loss to be arrested, and for severe cases that have not benefitted from outpatient care. In addition, some are admitted for the management of co-existing mental health problems such as severe depression. The threshold for admitting adolescents is lower than that for adults as their physical health is more readily compromised.³⁶ A small minority of admissions have to be compulsory.³⁷

As we discuss below, not everyone responds to treatment. Among those who do not respond are some patients who remain ill and severely impaired for many years. Their needs must not be forgotten.

6.2 Evidence-based treatment and prevention

Evidence-based treatment is possible in many cases. The leading treatments are psychological in nature and are primarily designed to be delivered on an outpatient basis.

6.3 Pharmacological treatments

There is a limited role for medication.^{38, 39} There are no empirically-supported pharmacological treatments for AN. A variety of drugs have been investigated, including antidepressants, antihistamines and, most recently, atypical antipsychotics,⁴⁰ but none has proved to be of clinical value. The situation is different in BN where antidepressant medication produces a decrease in the frequency of binge eating but it is not clear whether this effect is lasting.³⁹

A variety of drugs influence the frequency of binge eating in BED⁴¹ but they are not a first-line treatment, given the effectiveness of psychological interventions. With the exception of the anticonvulsant topiramate, they have little effect on co-morbid obesity.

6.4 Psychological treatments

We will start with the treatment of adults with BN as this has been the subject of most research.

Bulimia nervosa

While the disorder was originally described as 'intractable',¹ it is now clear that it can be treated, the leading evidence-based intervention being a specific form of cognitive behavioural therapy (CBT-BN).^{42, 43} This treatment was the first psychological treatment (for any condition) to be endorsed by NICE⁴⁴ and it is endorsed by many other national clinical guidelines.

Binge eating disorder

There is an emerging body of research on the treatment of BED.⁴⁵ It appears to respond well to a variety of psychological interventions including CBT-BN, interpersonal psychotherapy (IPT) and guided self-help.

All non-underweight eating disorders

Recently CBT-BN has been superseded by an 'enhanced' transdiagnostic version of the treatment termed 'CBT-E'^{46, 47} that can be used with any form of eating disorder. CBT-E appears to be more potent than its predecessor with two-thirds of non-underweight eating disorder patients (ie those with BN, BED or an OED) making a sustained full response despite an average duration of eating disorder of nine years^{48, 49} (see Figure 4.3). Similar response rates are being reported from 'real world' clinical settings.^{50, 51}⁵² The response rate among patients who are significantly underweight (BMI <17.5) is lower^{53, 54} but, as discussed below, it appears comparable to that obtained with other leading treatments.

Anorexia nervosa

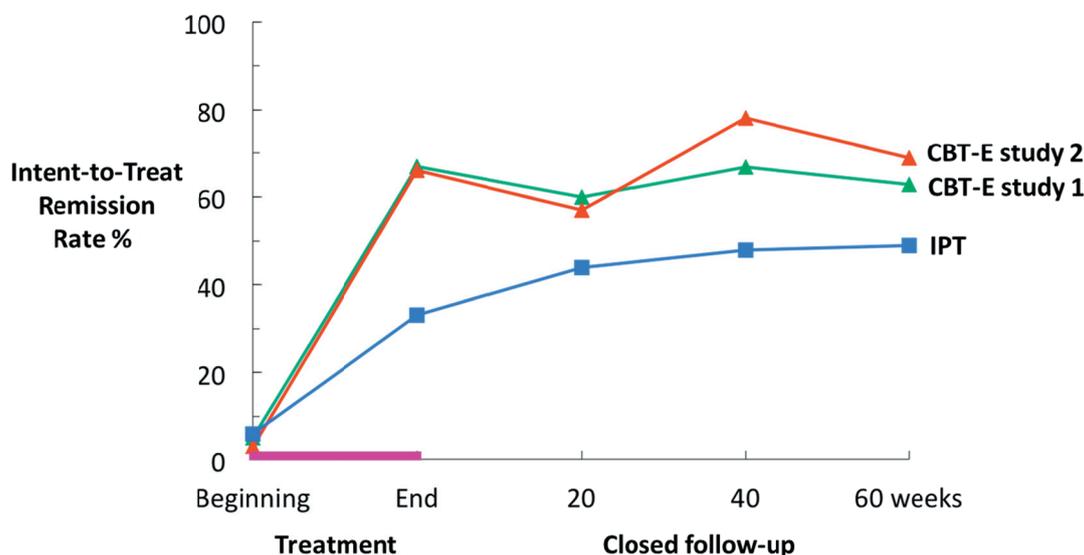
There have been relatively few studies of the treatment of adults with AN. In part this is because of logistical problems including its relative rarity and the lengthy duration of most interventions.⁵⁵ A number of treatments have modest evidence to support them,⁵⁶ including CBT,^{57, 58} CBT-E,^{53, 54, 59} a novel cognitive-interpersonal therapy,^{60, 61} a form of focal psychodynamic psychotherapy⁵⁹ and a combination of education, general clinical management and supportive psychotherapy.^{57, 58, 61} None of these treatments achieves a response rate comparable to those seen in BN, BED and the OEDs.

Younger patients

The focus of the research on younger patients has been on AN.^{45, 56} The sole evidence-based treatment is a specific form of family therapy commonly termed family-based treatment (FBT) or the 'Maudsley Method'.⁶² It requires the involvement of both the patient and his or her parents. FBT has a moderately strong evidence base and it achieves a full response rate in the region of 50%.

It is generally agreed that an alternative to FBT is needed, given the demands of the treatment in terms of parental involvement^{63, 64} and the importance of prompt treatment given the seriousness of the disorder and the unfavourable relationship between duration and treatment outcome.⁶⁵ One candidate is CBT-E⁶⁴ as it can be used with this age group^{54, 66, 67} and appears to be as effective.³⁵ A direct comparison of CBT-E with FBT would be of great interest, especially if moderators of treatment response were to emerge that would guide the allocation of patients to these two very different treatments.

Figure 4.3 Intent-to-treat remission rates obtained in non-underweight eating disorder patients treated with CBT-E (two separate samples) or IPT⁴⁹



Source Christopher G. Fairburn, Professor of Psychiatry, University of Oxford

There has been much less research on the treatment of BN in younger patients. FBT and guided self-help both have limited supporting evidence.^{68, 69} There have been no studies of the treatment of the OEDs in this age group. The research on the prevention of eating disorders is described in outline in Box 4.1.

Box 4.1 The research on the prevention of eating disorders

The research on the prevention of eating disorders has mostly focused on the evaluation of programmes designed to reduce concerns about body shape, a risk factor for developing an eating disorder. The group targeted has been adolescent girls and young women (12 to 29 years). It is clear that some of these programmes can reduce concerns about body shape⁷⁰ but it has not been demonstrated that this has an impact on the subsequent likelihood of developing an eating disorder.

This preventive strategy can be questioned as body image concerns are one among many risk factors for developing an eating disorder and the magnitude and universality of its contribution is far from clear.⁷¹ An alternative strategy would be to help adolescents avoid engaging in strict dieting as this behaviour is the prodrome of the majority of eating disorders. Unfortunately, it would be a complex message to convey, not least because it might appear to run counter to interventions designed to reduce the rate of obesity among this age group.

7. Eating disorders and the National Health Service

The UK has a strong international reputation for its research on eating disorders. The leading evidence-based treatments, FBT and CBT-BN, were developed in London and Oxford respectively. It is therefore disappointing that treatment provision within the NHS struggles to provide these treatments. There are a variety of problems: specialist services are patchy in their distribution; waiting times for treatment are frequently long; the evidence-based treatments are often not available or only in simplified unevaluated forms; outcome data are rarely or inadequately collected; there is, in some places, undue emphasis on inpatient care; and hospital stays are on average excessively long.⁷²

There is no single solution to these difficulties. An increase in resources would undoubtedly help and the recent provision of additional funds for improving access to treatment for young patients announced in the 2014 Autumn Statement is most welcome. However, the better use of existing resources might also make a substantial difference.^{73, 74}

8. Looking forwards

There is increasing evidence that psychological treatments for other mental health problems can be delivered online, with response rates not dissimilar to those obtained with face-to-face treatment.⁷⁵ Eating disorders may be particularly well suited to this mode of treatment delivery as the age group primarily affected is one that is used to accessing information and services in this way. Online, direct-to-sufferer, interventions might be especially useful in the early stages of an eating disorder when they could serve as a form of secondary prevention since they would sidestep many barriers to help-seeking such as shame and embarrassment, and the desire for anonymity. Research on such interventions is just beginning.⁷⁶ As matters stand, none of the online interventions for eating disorders has good evidence to support it^{70, 77} and, remarkably, there have been no studies of the many smartphone apps (over 800) that claim to be designed for this user group.⁷⁸ This is regrettable as they could do more harm than good.

9. Conclusions

Eating disorders are a cause of substantial physical and psychosocial morbidity among adolescent girls and young adult women. They are much less common among men. Their aetiology is complex and ill understood. There is a genetic predisposition, and certain specific environmental risk factors have been implicated. They typically begin in adolescence and may run a chronic course. Their effect is pervasive since they interfere with psychological, physical and social functioning. Once established, they are difficult to treat and impose a significant burden on health services. Evidence-based treatment is possible in most cases. The leading treatment for adolescents is a specific form of family therapy. A transdiagnostic form of cognitive behavioural therapy is the leading treatment for adults.

In our view, eating disorder services need to be thought through afresh, with the entire local population of sufferers being the unit of attention. The primary goal should be that patients receive well-delivered, evidence-based interventions as promptly as possible.⁷⁹ Other commitments, including looking after those who have not benefitted from treatment, should not distract or detract from this goal. With this model of treatment provision, eating disorders would be treated when they are most treatable, in the early years,^{8, 9} before they have become highly self-perpetuating and before secondary problems have developed. To achieve this goal, help-seeking needs to be accelerated possibly through the development of online resources designed to engage and inform. As noted above, it might be possible to treat simpler cases entirely online.

The role of inpatient services needs particularly careful thought as they are so costly. The research on their efficacy and utility provides meagre support for their use other than for physical stabilisation. Improvement tends to be largely limited to weight gain,⁸⁰ relapse is common⁸¹ and there is little support for lengthy admissions.^{82, 83} There will always be a need for inpatient provision for exceptional cases but it may well be possible to reduce the number and length of admissions and redeploy resources accordingly.

The development of optimal outpatient services will require substantial numbers of therapists to be appropriately distributed across the country. Some could be redeployed from inpatient units; others could be new recruits. Experience suggests that even CBT-E, one of the more complex psychological treatments, can be delivered by therapists with limited prior experience if they are properly trained and supervised. In the past their training would have been a rate-limiting step in scaling up treatment provision, but this may no longer be the case (see Box 4.2).

Box 4.2 Scaling up therapist training

The training of therapists is a major barrier to the widespread dissemination of psychological treatments.^{84, 85} The conventional method is labour-intensive and costly, and results in few people being trained. It typically involves an introductory 'workshop' given by an expert followed by supervision from someone proficient in the treatment. Neither is scalable. Few experts are available to give workshops nor are many people sufficiently experienced to provide supervision.

'Web-centred training' is a new form of training that provides a potential solution as it is designed to train large numbers of geographically dispersed therapists. It centres on the use of a specially designed website which describes and illustrates the treatment in great detail and incorporates tasks to help trainees grasp key concepts and master the main procedures. It can be used on its own (unguided training) or it can be accompanied by support from a non-specialist (guided training). Two such websites have been developed, one on CBT-E and the other on behavioural activation for depression.⁸⁶

The initial studies of web-centred training have focused on CBT-E. The experience to date (N = 130 trainees) suggests that it is popular and that by the end of the training period about half the trainees score over a validated threshold on an e-measure of therapist competence.⁸⁷

10. Authors' suggestions for policy

1. To accelerate help-seeking, online resources need to be developed that engage and inform sufferers, and provide treatment for simpler cases.
2. Outpatient services should focus on delivering the leading evidence-based treatments as promptly as possible. This will require substantial numbers of trained and supervised therapists to be appropriately distributed across the country.
3. The role of inpatient services needs to be reconsidered. It may well be possible to reduce the number and length of admissions, and to redeploy resources accordingly.

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Chapter 5

Pre-conception health

Chapter lead

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Pre-conception health

PLANNING PREGNANCY

Women will spend on average **30 years** preventing unplanned pregnancy

33%

of **births** are unplanned

45%

of **pregnancies** are unplanned

Long
Acting
Reversible
Contraceptives
are...

... > 20 times more effective in preventing pregnancy than pills or barrier methods and are **COST EFFECTIVE**

GETTING HEALTHY BEFORE PREGNANCY, FOR PREGNANCY

have a Body Mass Index (BMI) that is **18.5 to 24.9**

eat a healthy diet which includes folic acid

be physically active

address mental health problems

stop smoking

avoid alcohol and recreational drugs



EFFECTS OF MATERNAL OBESITY



For the Mother

- decreased fertility
- increased risk of miscarriage
- increased risk of gestational diabetes
- increased risk of perinatal complications

For the Fetus

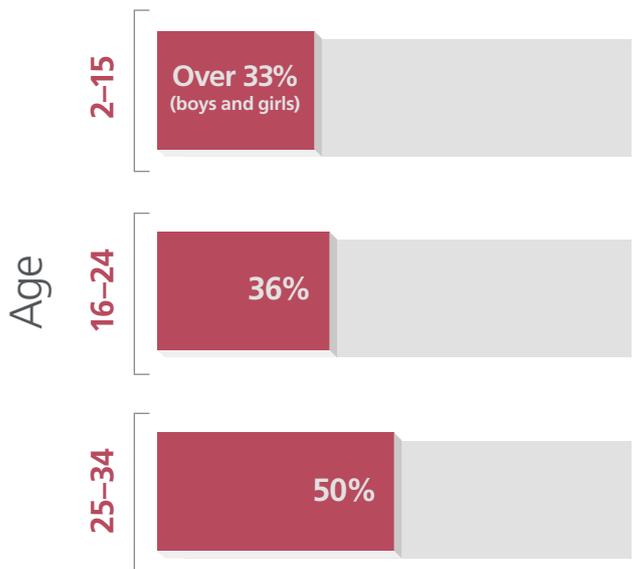
- increased risk of stillbirth
- increased risk of metabolic abnormalities
- increased risk of developmental abnormalities

For the Offspring

- increased risk of obesity
- increased risk of diabetes
- increased risk of hypertension (high blood pressure)



PROPORTION OF OVERWEIGHT OR OBESE WOMEN IN ENGLAND



1. Key statistics

- In England in 2013, over 36% of women aged 16–24 and 50% of women aged 25–34 were overweight or obese.
- In 2013, more than one-third of children aged 2–15 were overweight or obese.
- Having multiple early-life risk factors is associated with a more than four-fold increased risk of being overweight or obese in later childhood.
- Although more than two-thirds of pregnancies leading to live births are planned to some degree, the majority of women do little to change their lifestyle to prepare for pregnancy.

2. Overview

In England we face an increasing burden of non-communicable diseases (NCDs), especially those related to obesity, including type 2 diabetes, cardiovascular disease, asthma and endometrial cancer. This chapter highlights the evidence which has led to recognition of the missed opportunity to promote health in women of reproductive age, particularly in the pre-conception period. It also highlights the move towards identifying effective interventions to improve the health of mothers and children. Key points include the following:

- The recent increase in obesity among women of reproductive age – in England in 2013, 50.8% of women aged 25–34 were overweight or obese – not only influences their health,¹ but also increases the risk of complications during pregnancy and is likely to compromise the health of their children² (Figure 5.1).
- Maternal obesity is one of several influences that appear to underlie the fetal or pre-conceptual origins of later risk of NCDs,^{3,4} and it is now widely recognised that a focus on pre-conception health offers an important newly recognised opportunity for improving the health of the nation.
- While pregnancy no longer carries the significant risk of death that it did in the early years of the 20th century, unplanned pregnancy remains common in women across the reproductive age range, with 57% ending in termination.⁵
- In 2013/14 there were about twice as many referrals for psychological therapy in women aged 15–24 as in men.⁶ Maternal mental health before and during pregnancy is a particular cause of concern,^{7–9, 10,11} representing a further opportunity for improving the health of women.
- There are significant economic benefits which will accrue from meeting the challenge of preventing NCDs, which incur considerable health costs. For the risk factor obesity, the McKinsey Global Institute estimates that a programme of interventions to reverse its rising prevalence could save the NHS \$1.2 billion/year.¹² NCDs associated with obesity can reduce economic productivity, and obesity in children and adolescents can impair neurocognitive development.^{13,14}
- Meeting the challenge posed by obesity and NCDs has important social and equity implications, because the exacerbating factors are particularly prevalent in women with low educational attainment or socio-economic status,¹⁵ and in some ethnic and long-term (>1 year) immigrant groups.^{15,16} NCDs generate a vicious cycle which perpetuates and may widen social inequalities in health.¹⁷

3. Current status of pre-conception healthcare

The majority of future parents do little or nothing to prepare for pregnancy¹⁸ even though more than two-thirds of pregnancies leading to births in the UK are planned to some extent.¹⁹ A high proportion of women have an unhealthy lifestyle before pregnancy,²⁰ with poor diet, low levels of physical activity, smoking, excessive alcohol consumption and use of recreational drugs.²¹ Poor mental health is common in individuals with an unhealthy lifestyle.²² Moreover, many women are affected by domestic violence before and during pregnancy, with adverse impacts on obstetric, maternal and child outcomes.

There is evidence that early signs of cardiometabolic risk in children such as carotid intima-media thickening and increased aortic pulse wave velocity are related to their mother's nutrition in pregnancy²³ and, conversely, that a healthy diet in the mother can have beneficial effects on childhood cardiovascular function.²⁴

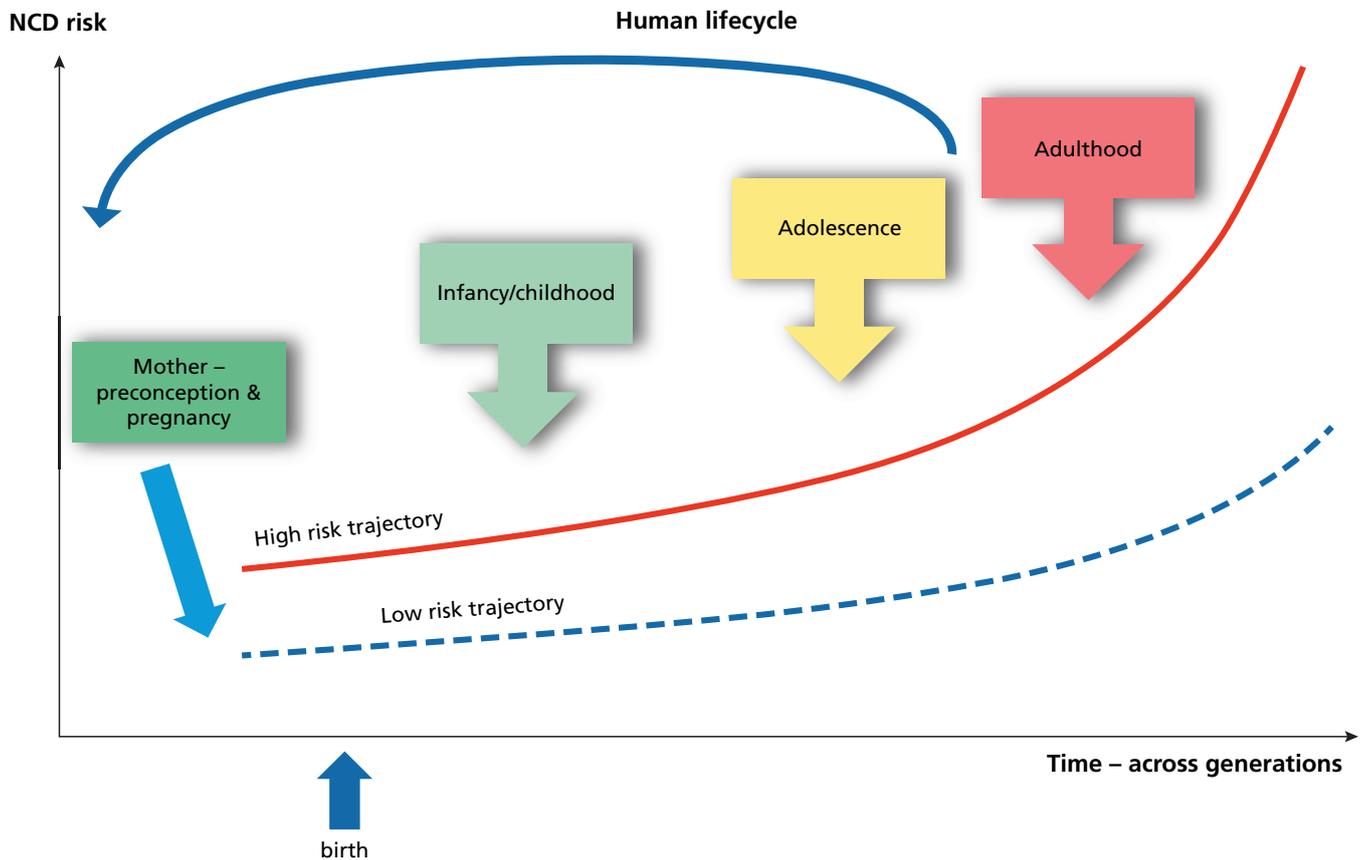
The challenge of pre-conception healthcare is particularly prominent in adolescents (those aged 10–19). Adolescence is a period when many behaviour patterns become established.

Many young people are overweight or obese²⁵ and have markers of cardiovascular risk such as an abnormal lipid profile, insulin/glucose levels and blood pressure.²⁶

Beyond the health implications for the individuals themselves, suboptimal behaviour patterns and cardiovascular risk in adolescents have repercussions for the development and health of the next generation, who will start life on a steeper trajectory of NCD risk (Figure 5.1). Access to and uptake of healthcare, and contraception to assist in planning the timing of pregnancy, are fragmentary in women of childbearing age, especially in adolescents (Box 5.2), and it is not surprising that adolescent pregnancies often have poor outcomes such as low birthweight.²⁷ If they consider their health, adolescents defer any action to improve it until some indeterminate time in the future.^{28,29} Yet they and their partners want the best for their children (see Box 5.3), so there is clearly an unmet need.

Promoting adolescent health should reduce health inequalities^{30,31} and have beneficial implications for the rights of women, eg for contraception and the right to education and work, and also those of children^{32,33} (see also Chapter 12, 'A Human Rights Approach to Women's Health'). Most adolescents have little or no knowledge of the need to prepare for pregnancy and may not be sufficiently physically or psychologically mature to support it.³⁴

Figure 5.1 Life course model of Non Communicable Disease (NCD) prevention, showing the importance of intervention in adolescents and young adults



Box 5.1 Accessing maternity care early

Pregnant teenagers and young fathers are less likely than older people to access maternity care early in pregnancy.

Source Department for Children, Schools and Families (2008). *Teenage parents: who cares? A guide to commissioning and delivering maternity services for young parents.*

In 2013/14, 75% of pregnant women were seen for their first antenatal assessment within 12 weeks of gestation, where this date is known and data are available. Data for about 30% of deliveries are not known.

Source Health and Social Care Information Centre

Box 5.2 Quote from mother, aged 30

'I don't know, you just assume that you just get pregnant and then you go to your GP and everything falls in place from there. I didn't know that there were things that you should be doing prior to becoming pregnant. You don't really plan it... although I was planning it.'

Source Barrett G. Why do women invest in pre-pregnancy health and care? A qualitative investigation with women attending maternity service. *BMC Pregnancy and Childbirth* 2015: In Press.

Box 5.3 The wish to be good parents

'Some time ago, I asked to meet a group of 15 year old pupils in one of Birkenhead's most challenged schools... I asked each of them to list for me which six outcomes they most wanted to gain for themselves from attending school.'

'Their replies both shocked and delighted me. Without exception, all of these young citizens stated that they wanted their school to be a safe place, to help teach them what was involved in building long-term friendships and to equip them with the necessary skills to gain a good job. Most surprisingly, all of the pupils listed as one of their remaining requests the wish to be taught how to be good parents.'

Source Field F (2010). *The foundation years: preventing poor children becoming poor adults. The report of the Independent Review on Poverty and Life Chances.* London: TSO.

4. Why a new focus on pre-conception is so important

Increasing evidence indicates that the pre-conception period is a crucial time for development of future NCD risk in the offspring.^{35,36} Fortunately, however, many risk factors known to affect offspring development adversely are modifiable. Healthy pregnancies are favoured by entering pregnancy with a normal BMI, healthy diet (eg eating fruit or vegetables at least three times each day), being physically active and in good mental health, not smoking, and avoiding alcohol and recreational drugs.¹ Obese women have lower fertility rates and greater risk of early miscarriage,¹ and the oocytes and early embryos of obese mothers show an increased incidence of metabolic and developmental abnormalities.³⁷

During pregnancy, obesity confers greater risk of metabolic disease such as gestational diabetes, of perinatal complications, and of later NCDs such as diabetes and hypertension in both the mother and her child.³⁸ Conversely, inadequate food intake and low maternal weight are linked to low birthweight,³⁹ as is micronutrient deficiency, especially of folate.^{34,40} While some health professionals give advice on the need for adequate folate status in preventing neural tube defects, many do not,^{19,41} and few are aware that it is routinely needed for good fetal growth.^{27,42} Smoking in pregnancy is associated with poor fetal growth and low birthweight, and with obesity in childhood.⁴³⁻⁴⁵ Although there are substantial regional differences, smoking has generally declined in the UK. Nonetheless, in 2014 the Health and Social Care Information Centre reported that 12.7% of women self-identified as smoking in pregnancy.⁴⁶

As noted in the *Annual Report of the Chief Medical Officer 2012. Our children deserve better: prevention pays*,²⁴ there is growing awareness of the Developmental Origins of Health and Disease concept, and with this come new opportunities for implementation of interventions to halt or reverse upward trends in NCDs.⁴ This research into the developmental origins of health and disease has shown how suboptimal elements of the environment to which the embryo, fetus or newborn baby is exposed, such as unbalanced maternal diet, poor mental health, obesity, smoking or stress, can affect the baby's growth and development.^{11,47-49} While the effects of these factors are not necessarily obvious at birth, they can influence the long-term risk of obesity, diabetes and cardiovascular disease, as well as developmental and psychological disturbances, especially when the child grows up in an obesogenic environment.⁴ Asthma and other lung diseases, mental illness, cognitive decline and some forms of cancer have also been linked with unhealthy early life environmental exposures.⁴ This novel trans-generational mode of disease 'inheritance' from parents to children is likely to account for a greater proportion of risk in the population than fixed genetic effects;⁵⁰ moreover, it provides new scope for prevention.⁵¹

If public health interventions to prevent obesity, to optimise nutrition, physical activity, and mental and sexual health, and to stop smoking and use of recreational drugs do not start before a woman becomes pregnant, later interventions to reduce NCD risk in the next generation may be less effective (Figure 5.2). Modelling by health economists demonstrates the substantial financial leverage which can be gained from investing in health at this time in the life course.^{52,53}

Once pregnant, many women are motivated to adopt healthy behaviours,⁵⁴ but the first contact with antenatal care may come too late to ensure a healthy pregnancy and longer-term outcomes: for example, a link has been shown between poor first trimester fetal growth and increased cardiovascular risk in primary school children.⁵⁵

Promotion of health before conception requires that the general public and health professionals become better acquainted with the ways by which this is likely to be achieved. Current delivery of pre-conception care by health professionals is patchy,¹⁹ and women's compliance with pre-conception health guidelines remains low¹⁸ even among women with a clear intention of becoming pregnant, revealing multiple missed opportunities for improving maternal and child health.¹⁹

5. What can be done to promote pre-conception care and health?

Box 5.4 Elements for successful childhoods

'Essential elements for successful childhoods include engaged, supportive parents and teachers, and early health, nutrition and learning. We should not underestimate the role of the parent and the power that comes from providing parents with information, resources and choice. Ensuring that parents have the knowledge and resources for providing a stimulating home environment is just as important, if not more important, as anything that happens in the classroom when children enter school.'

Source Heckman J. Speech at the White House: www.heckmanequation.org/content/white-house-summit-early-education

5.1 Focus on pregnancy planning

A key step in improving pre-conception health and care is to recognise that most pregnancies leading to live births are, at least to some extent, planned,⁵⁶ and that the window of opportunity to intervene is often much wider than assumed.⁵⁷ Women seldom volunteer to health professionals that they are planning to become pregnant, but they frequently come into contact with services for related reasons, eg buying a fertility or pregnancy test from a community pharmacy, attending a community contraceptive service for removal of a contraceptive device or implant, or visiting their GP or early pregnancy unit after miscarriage. These present ideal opportunities for pre-conception health interventions, such as giving simple written information, advice and supplies (eg folic acid and vitamin supplementation) or access to mobile health platforms to promote pre-conception health, but these are frequently missed.

Another missed opportunity includes baby checks for infants or pre-nursery children, when about one in five mothers are likely to be planning another pregnancy.¹⁹ By asking about pregnancy intention in these contexts, healthcare professionals could identify many more women wishing, albeit at various levels of intent, to conceive again in the near-to-medium future.

Unplanned pregnancy is associated with a range of adverse outcomes, including low birthweight, prematurity and postnatal depression.^{58,59} The importance of identifying women with greater or lesser levels of pregnancy planning

is underscored by evidence that pregnancy planning is not a binary ('yes or no') concept. Using a validated measure (the London Measure of Unplanned Pregnancy, or LMUP, which scores the degree of pregnancy planning from 0 to 12) in routine antenatal care could help UK health professionals to identify women who could benefit from additional support to minimise the risk of such adverse outcomes (see Box 5.5).

Box 5.5 Monitoring interventions

Monitoring the effectiveness of intervening at scale is important, and can be achieved by using a validated robust measure that scores (from 0 to 12) the extent to which a current or recent pregnancy was planned (the London Measure of Unplanned Pregnancy – www.lmup.com). The measure is sensitive enough to detect changes in pregnancy planning and, by definition, the incidence of unplanned pregnancy over time, across diverse populations and in response to intervention. Other outcomes which could be included in a package to monitor effectiveness include the mother's BMI, gestational age at booking and whether she is taking folic acid supplement.

Box 5.6 Information in different formats

'I like the apps really. Yeah, I've had loads of leaflets, loads of books and booklets and stuff, especially from my family nurse. She gave me loads of leaflets and booklets. And did you read any of the books or the leaflet...? No, I didn't actually. If it come with a video or something I probably would have watched it, but it's just reading. But not if it's all reading... books...? Yeah, it's boring reading books, no one wants to read a book.'

Source LYW5 interview transcript; Rundle et al. (2014). *An exploratory study of young women's food choices and compliance with supplementation recommendations during pregnancy*. Report to Tommy's Diet and Teen Pregnancy Steering Group.

Box 5.7 Responses from Southampton teenagers to the question:

Thinking about yourself and your own life, what is the most important thing you have learnt from coming to LifeLab today?

'That at our age if we change our lifestyle then we can more than halve our chance of getting an illness later on in life.'

'How my lifestyle will affect my children.'

'I need to start losing a little weight and have more control over my life.'

'That your child's health starts when your life starts.'

'How unhealthy my lifestyle actually is and the small changes that need to be made just to make sure I'm at less of a risk.'

'That I'm a lot more unhealthy than I thought I was, and as a result I may take a healthier life style in the future.'

Source Grace M, Woods-Townsend K, Griffiths J, Godfrey K et al. Developing teenagers' views on their health and the health of their future children. *Health Education* 2012: 112; 543–559.

5.2 Bring pregnancy prevention and pregnancy planning under one reproductive health umbrella

The extensive benefits of good contraceptive care are often underappreciated. At the global level, use of contraception has already reduced maternal deaths by 40% and ensuring access to contraception for all women wishing to avoid a pregnancy worldwide would reduce maternal deaths by a further 30%.⁶⁰ Contraception is also important in the postnatal period to avoid short inter-pregnancy intervals: an interval of less than six months is an independent risk factor for preterm delivery and neonatal death in the next pregnancy.⁵

In the UK, teenage pregnancy rates have been falling for the last two decades but, for women of all ages, around a third of all births and 45% of all pregnancies are unplanned or ambivalent, and termination rates have changed little.⁶¹ Social and demographic changes have resulted in many women choosing to delay pregnancy or have no children.⁶² Longer intervals between first sexual intercourse and childbearing mean that women in Britain will spend on average 30 years of their life preventing unplanned pregnancy.⁶² Long acting reversible contraception, which includes intrauterine contraceptives, contraceptive implants

and injections, is 20–100 times more effective in preventing pregnancy than contraceptive pills or barrier methods and is cost effective.⁶³ Nonetheless, many women still think that their contraceptive options are limited to condoms or the pill. Commissioning of contraceptive services in England has become very fragmented since the introduction of the Health and Social Care Act 2012, which has adversely influenced access to and choice of contraception for women wishing to avoid pregnancy, as highlighted by the Advisory Group on Contraception report, *Sex, Lives and Commissioning II*.

Most women experience a range of pregnancy intentions from complete avoidance to attainment of pregnancy at different stages in their lives. The implication for health services is that, by strengthening the provision and alignment of contraceptive care and pregnancy planning, women could be helped to have children by choice rather than chance, and the authors suggest that their pre-conception health could be simultaneously improved.

Currently, the organisation of women's health services reflects the organisation of traditional medical specialties rather than an integrated approach to sexual and reproductive healthcare. For example, the lack of cohesion between family planning services and maternity care means that everything between prevention of pregnancy and care during pregnancy is often overlooked.^{63,65}

The four Ps (pregnancy prevention, pregnancy planning, pregnancy preparation, and preparing for parenthood) (Box 5.8) constitute unifying aspects of reproductive and family health that can be addressed at multiple points during the life course when women's interactions with health services are relatively frequent and predictable (compared with men). Considering the four Ps provides an example of an integrated approach which could overcome the current 'silo working'.

Discussion of the four Ps, rather than just contraceptive methods, could become a core element of school sex and relationship education. Primary and community healthcare providers (including GPs, nurses, pharmacists, community midwives, health visiting teams, and sexual and reproductive health specialists) need only a modest level of training, as in the Community Sexual and Reproductive Health (CSRH) curriculum, to improve their confidence and skills in discussing pre-conception health and care^{66,67} (Box 5.9). Healthcare providers in these settings have the opportunity to ask women whether they are considering having a baby, especially in those with existing health conditions such as diabetes, epilepsy and mental disorders, and in women requesting pre-pregnancy advice, pregnancy tests or removal of intrauterine contraceptives or implants. There is experience in the USA where promotion of a Reproductive Life Plan is more widely used to assist couples in making informed decisions about the intention to have children, with a view to reducing infant mortality and ethnic disparities in reproductive health,⁶⁸ and an oral contraceptive pill containing folic acid is available.

Box 5.8 The four Ps

- Pregnancy planning
- Pregnancy prevention
- Pregnancy preparation
- Preparing for parenthood

Box 5.9 Healthy Conversation Skills

Every day millions of women of childbearing age in the UK have contact with health and social care practitioners. These contacts provide opportunities to engage women in thinking about their health and in planning for pregnancy. Healthy Conversation Skills, a brief programme of training developed in Southampton, equips practitioners with skills in engaging and motivating people to change their lifestyles. The training changes the way practitioners interact to a style that empowers clients to problem-solve and make lifestyle changes, and increases women's confidence that they can adopt health-promoting behaviours.

Source Lawrence W, Black C, Tinati T, Cradock S et al. 'Making every contact count': evaluation of the impact of an intervention to train health and social care practitioners in skills to support health behaviour change. *Journal of Health Psychology* 2014.

5.3 Improve health literacy and behaviours

Recent data show that levels of physical activity among teenagers are falling: in 2008 14% of girls aged 13–15 met the recommended level of physical activity; in 2012 this had fallen to 8%.⁴⁶ Health literacy and healthy behaviours (coupled with the avoidance of harmful behaviours) in women of reproductive age could be influenced by campaigns using a range of media including the internet, social media and app-based programs.⁷⁰ This could empower women not only by improving health literacy but also motivation⁷¹ where it is poor. Such a campaign is likely to be more easily responded to by women who are media-literate, often those with greater educational attainment and socio-economic status, and therefore specific measures will be needed to access hard-to-reach groups, including migrants and ethnic minorities (for example, via family intervention as opposed to traditional clinical care⁷²).

Formal educational programmes delivered through schools have only had small effects on, for example, levels of obesity.⁷³ However, integration of new curriculum components with context-specific learning may be a promising way of improving the capacity of young people to obtain and understand the basic health information and services needed to make appropriate health decisions (ie their health literacy) and of motivating them to change their behaviour.⁷⁴⁻⁷⁹

Public health interventions focused on the prevention of obesity in children have achieved some success.⁸⁰ Recent

data show that 48% of 16–24 year olds use fitness apps on a regular basis, although only 12% use the internet to search for healthy living information (source: TNS face-to-face omnibus survey, 17–21 January 2014, in HSCIC report, *The health and care of young people*, June 2015). Interventions may be even more effective if positive messages about health promotion through physical activity, diet and a less sedentary lifestyle, as opposed to negative messaging about risk, are used⁸¹ (see also Chapter 4 OF THIS REPORT, ‘Eating disorders’). For children and adolescents, interventions to achieve a healthy BMI, better diet, physical activity and mental wellbeing, with the avoidance of smoking, alcohol and recreational drugs, could also be more effective in family^{82,83} or combined school and community settings.⁵⁷

The evidence about behaviour change coming from health psychology research suggests that interventions to alter ‘choice architecture’, such as product labelling, sizing and placement in retail outlets, can change some population-level behaviours in ways that improve public health.⁸⁴ Co-creation of interventions with both client and provider groups in order to meet the needs of both⁸⁵ may reduce the risk of introducing interventions that are irrelevant to the target population or the imposition of extra workload on already hard-pressed health professionals.

5.4 Use multi-agency working to build effective partnerships

The importance of partnerships involving schools, further education, employers, parents and healthcare providers is demonstrated by the Teenage Pregnancy Strategy.⁸⁶ A model of co-production is more likely to meet the needs and aspirations of the public⁵⁶ and is now seen as crucial to improving public services.⁸⁷ This co-production could include schools and schools of education, programmes for continuing professional development of teachers, curriculum modification by the Department of Education and teaching organisations, and local government, community and commercial organisations for the provision of facilities for children, especially for physical activity. In addition, schools could be linked with the wider community and family activities, including sports, recreation and faith programmes, but also higher education institutions, healthcare providers and researchers.

Engagement of programmes in adolescent health, sexual and reproductive health, pre-conception, antenatal and postpartum services could provide a pathway of healthcare which allows multiple points of access and continuity of care. This might be achieved through sustained provision of community health facilities such as Sure Start and Children’s Centres as well as youth and other social services.

Partnership with charitable and philanthropic organisations, the media and some carefully regulated private sector organisations, along with role models or celebrity endorsement, may help to give concepts of pre-conception health visibility and impact, and to adapt them for various ages and settings.

6. Conclusion

Awareness of pre-conception health, pregnancy prevention, pregnancy planning and uptake of interventions before pregnancy are related but distinct issues. We believe that improvement in all areas is required for a step change in pre-conception health and pregnancy outcomes (reproductive health) and that this in turn calls for a comprehensive strategy directed at schools, youth services, health services and the wider public. In our key messages for policy we make five interrelated suggestions. These suggestions form part of the opportunity for a new wave in public health.⁸⁸ Other current proposals would support this more specific agenda⁸⁹ and they are in accord with current thinking in global health promotion by the World Health Organization and other bodies,^{31,90-93} the UN Secretary General’s Every Woman Every Child initiative⁹⁰ and the Sustainable Development Goals.⁹⁴ There is an opportunity for the UK National Health Service to improve its population’s health by increasing pre-conception health promotion.

7. Authors' suggestions for policy

1. Make the pre-conception health of women of reproductive age a public health priority.

This could comprise development, piloting and evaluation of packages of interventions as discussed above, coupled with an awareness-raising campaign to make the assessment of pregnancy prevention and promotion of pre-conception health a wide-reaching movement. Embedding a truly multi-disciplinary approach demands multi-departmental engagement, including the Department of Health; the Department for Education; the Department for Communities and Local Government; the Department for Culture, Media and Sport; and the Department for Business, Innovation and Skills. This would permit development of the plan, setting clear targets and deliverable dates and establishing evaluation procedures.

2. Create a new integrated health delivery system.

This would aim to meet the needs of women of reproductive age in the pregnancy prevention, pre-conception, antenatal, and intra- and interpartum phases of their lives, involving the full range of health professionals. Integration of this system with sexual and reproductive health services, primary care and wider community-based opportunities would permit the delivery of clear, consistent advice and care. This could be developed with the relevant health professional groups (including GPs, midwives, health visitors, consultants in sexual and reproductive health, obstetricians and gynaecologists) to ensure that it fits with their respective professional roles and motivations, and to avoid the external imposition of extra duties and long check lists on already heavy workloads.

3. Strengthen commitment to integrating pregnancy prevention, pregnancy planning and pregnancy care.

This could be achieved by creating a single organisation, or a closer alliance of the Faculty of Sexual and Reproductive Health and the Royal College of Obstetricians and Gynaecologists, which recognises the leadership and contribution of both community-based specialists in sexual and reproductive health and hospital-based obstetricians and gynaecologists in achieving a broader vision of women's health.⁹⁵

4. Bring together key data.

Key data (including use of contraception, pregnancy outcomes, sexually transmitted infections (including HIV), diagnoses, and cervical screening/vaccination and LMUP data), which are currently held separately by the Health and Social Care Information Centre and Public Health England, should be brought together to enable changes in reproductive health outcomes to be monitored, over time and between population subgroups, by local health and public health services.

5. Promote health literacy about the importance of the pre-conception period.

This could be done through education programmes in schools such as sex and relationship education linked to community-based initiatives involving a range of organisations and sponsors. This investment would draw on experience, such as the Family Nurse Partnership programme⁹⁶ which is based on the US Nurse-Family Partnership, with a range of outcomes from pregnancy spacing, partner violence, childcare and parental mental health, and would need to be evaluated through short-term outcomes used for existing pre-conception interventions.^{86,97-99}

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Chapter 6

Prenatal screening

Chapter lead

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Prenatal screening

GESTATIONAL DIABETES CAN LEAD TO

MOTHER

↑ 25%

INCREASE IN IMMEDIATE HEALTHCARE COSTS

↑ 15%

INCREASE IN HEALTHCARE COSTS FOR 2-5 YEARS

↑ x7

RISK TYPE 2 DIABETES IN LATER LIFE



BABY

MACROSOMIA
(BEING LARGE FOR GESTATIONAL AGE)

£2,392

DIRECT NEO-NATAL COSTS PER INFANT

SHOULDER DYSTOCIA
LIFE THREATENING FOR BABY
(CAN CAUSE INJURY, HYPOXIA, CEREBRAL PALSY AND STILLBIRTH)

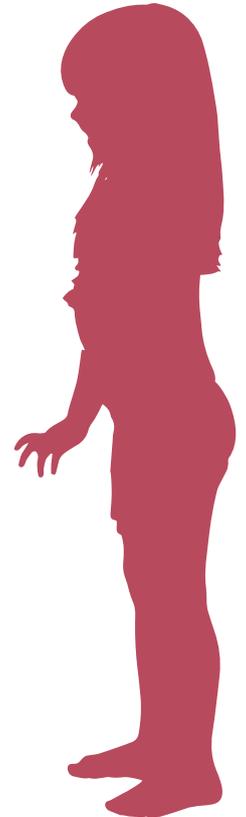
OFFSPRING

OBESITY

AND OR

METABOLIC DYSFUNCTION

WHICH PERSIST INTO ADULTHOOD



1. Key statistics

- The majority of adverse outcomes (eg very preterm deliveries and stillbirths) are not related to known risk factors; eg less than 20% of the variability in the risk of stillbirth can currently be detected at the start of antenatal care.
- The costs of long-term morbidity and mortality from adverse perinatal outcomes are extremely high; eg the direct sequelae of preterm birth cost the public sector £1.24 billion annually, with an additional £2.48 billion indirect costs (including later costs such as education and loss of parental work).
- Litigation related to maternity care accounts for a third of all NHS claims: a recent decade (2000 to 2010) of maternity claims cost more than £3.1 billion, with some individual claims >£6 million.
- Improved screening has reduced the rate of live births of children with Down's syndrome in the UK to 54% of expected values, with fewer losses due to unnecessary invasive tests.
- Each year in the UK, approximately 7,000 babies are stillborn or die in the first year of life. Many could potentially have been saved had they been detected as growth-restricted *in utero*. Immediate peripartum costs for each growth-restricted term infant are £2,650 greater than for an infant of normal growth. Fetal growth restriction increases the risk of cerebral palsy, which carries an estimated lifetime cost of at least £588,000 per child.

2. Introduction

Total maternity care spending in England exceeds £2.5 billion annually,¹ yet the amount currently spent on prenatal screening is just under £4 million.² Screening that can improve detection of pregnancies at risk of adverse outcomes so that they will consequently receive targeted care has the potential to improve outcomes and be highly cost-effective. In this chapter, we consider prenatal care to involve all aspects of care up to birth, including intrapartum care. We illustrate these issues using four common conditions:

- gestational diabetes
- preterm birth
- placental dysfunction
- complicated first birth

2.1 Immediate costs of obstetric pathologies

Gestational diabetes

Gestational diabetes mellitus (GDM) is increasingly prevalent due to changes in the childbearing population (eg increasing maternal age and obesity^{3,4}), as well as changing thresholds for diagnosis. GDM carries increased risks of adverse perinatal outcomes, particularly shoulder dystocia and stillbirth. The immediate healthcare costs of gestational diabetic pregnancies were increased by 25% (£1,300) and 34% (£2,000) respectively compared with women without GDM in Finnish and Irish cohorts.^{5,6}

Preterm birth

Preterm birth accounts for 60–80% of neonatal deaths of normally formed babies⁷ and is among the top 20 UK causes of premature mortality.⁸ Over 60,000 infants annually in the UK require neonatal intensive care. For every individual baby born healthy but before 30 weeks, basic care costs typically run to >£20,000,⁹ and many times higher in cases with multiple co-morbidities. The direct sequelae of preterm birth cost £1.24 billion annually, with an additional £2.48 billion indirect costs (including loss of parental work, education costs etc).¹⁰ Preterm births occur both spontaneously and via iatrogenic intervention; however, currently available data in the UK do not allow a reliable separation of the attributable costs. A major part of the economic cost of fetal growth restriction and severe pre-eclampsia arises from iatrogenic preterm delivery.

Placental dysfunction

Stillbirth and fetal growth restriction (FGR) are important direct sequelae of placental dysfunction. Stillbirth rates in the UK remain higher than might be expected in a high-income country, at 4.2/1,000 births,¹¹ compared with the average of 3.9/1,000 births in high-income regions worldwide.¹² The total direct antenatal, intrapartum and postnatal cost of delivering a term baby known to have FGR is approximately

£2,650 more than a normally grown baby.¹³ Placental dysfunction may also result in pre-eclampsia, the immediate additional costs of which run to £9,000 per affected pregnancy.¹⁴

Complicated first birth

For mothers, a complicated first birth carries increased morbidity, including haemorrhage, infection and prolonged hospital stay.^{15, 16} The rate of intrapartum Caesarean section is approximately five times higher in nulliparous women than in women who have had a previous vaginal delivery. The immediate episode cost of a primary Caesarean section has been estimated to be between £500 and £1,500 higher than the cost of a normal delivery.¹⁷ In excess of 45,000 first-time mothers are delivered by Caesarean annually, representing a total increased cost of £36 million.¹⁸ Approximately 8% of stillbirths occur intrapartum, resulting in the loss of approximately 300 babies annually.

2.2 Maternity care and litigation

One in 600 births in the UK results in a clinical negligence claim. The average cost of insurance against litigation per delivery in the UK is £700 (20% of the total delivery cost).^{1, 19} Litigation related to maternity care accounts for a third of the total value of all NHS claims. Clinical negligence claims with an incident date of between 1 April 2000 and 31 March 2010 resulted in 5,087 maternity claims totalling more than £3.1 billion, with some individual claims >£6 million.¹⁹

2.3 Life-long consequences of obstetric pathologies

Gestational diabetes

Annual healthcare costs for women with GDM remain 15% higher (an additional £487 per woman per year) for two to five years post-delivery than for normo-glycaemic pregnancies, regardless of birth outcome.²⁰ Women diagnosed with GDM have a seven-fold increased risk of developing type 2 diabetes in later life,²¹ with associated annual costs per woman of at least £2,644.²² For infants of diabetic mothers, long-term morbidity from adverse birth outcomes, particularly hypoxia secondary to shoulder dystocia, may be profound (see Case study A) and costly. The average direct neonatal cost of a macrosomic infant is £2,392.²³ The hyperglycaemic intrauterine environment may alter developmental programming, leading to increased rates of obesity and metabolic dysfunction in childhood and adult life.^{24, 25}

Preterm birth

At least 25% of children born before 27 weeks have neurodevelopmental impairment at 3 years.²⁶ In childhood, extreme preterm birth (<26 weeks) carries additional costs of £5,658 annually per child²⁷ and, by age 11, each survivor still requires £2,500 extra public spending annually.²⁸ Complications from preterm birth account for 217 disability-

adjusted life-years per 100,000 individuals.⁸ Impairment requiring ongoing economic assistance into early adulthood is strongly related to the degree of preterm birth: 13.2% for births at 24–28 weeks and 5.6% for births at 29–32 weeks. However, mild preterm birth (33–36 weeks) and early term birth (37–38 weeks) accounted for 74% of the total disability associated with preterm birth, due to their high prevalence. The total societal costs (benefits required and taxes lost) which could be attributed to early delivery in 2002 in Sweden was estimated at €65 million.²⁹

Placental dysfunction

Children born below the 3rd centile for birthweight have double the rate of special educational needs at school compared with children of average weight,³⁰ although the economic costs cannot reliably be isolated. Furthermore, being born small and undergoing catch-up growth in childhood is a risk factor for disease later in life, primarily cardiovascular disease, obesity and metabolic dysfunction – a phenomenon known as developmental programming.³¹ For mothers who experience pre-eclampsia during pregnancy, there is a 3.7-fold increased risk of hypertension and a ~2-fold increased risk of ischaemic heart disease.³² Achieving a 1% reduction in the risk of cardiovascular disease for the population as whole by any means would result in £30 million annual savings in healthcare spending.³³

Complicated first birth

Some 5% of births in the UK are complicated by hypoxia.¹⁸ More than 3,000 quality-adjusted life-years are lost annually to cerebral palsy from obstetric complications resulting in fetal hypoxia, at estimated costs of £62.9 million.³⁴ Primary Caesarean sections (defined as a Caesarean section performed for a woman who has not had a previous Caesarean delivery³⁵) are the single largest indication for subsequent elective Caesarean sections in the UK. Between 0.8% and 1.5% of women develop abnormal placentation in a subsequent pregnancy after a primary Caesarean, carrying substantial risks including severe haemorrhage and intensive care admission.³⁶

3. The consequences of failing to apply what we know

3.1 Gestational diabetes – a case study

A 32-year-old woman of Bangladeshi origin was designated 'low-risk' in her first pregnancy and had routine midwife-led maternity care. A glucose tolerance test for gestational diabetes was not performed. She laboured spontaneously at term. After prolonged pushing, forceps delivery was undertaken. The head was delivered, but the shoulders failed to follow (ie shoulder dystocia). The 4.1 kg baby was eventually born in poor condition after 6 minutes of hypoxia. Full resuscitation was performed; however, there was evidence of hypoxic-ischaemic encephalopathy on MRI scan. At 5 years old, he has moderate neurodevelopmental delay. Maternal blood sent on the day following delivery demonstrated elevated levels of glycated haemoglobin, and hence a very high likelihood of undiagnosed gestational diabetes during the pregnancy.³⁷

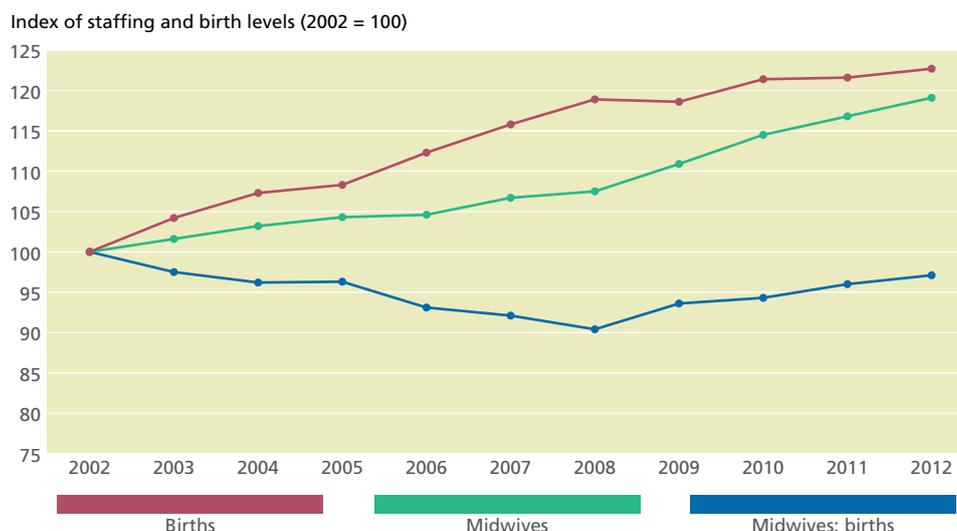
This case illustrates the importance of stringent application of screening tests for gestational diabetes. An oral glucose tolerance test is recommended for all women at high risk of developing gestational diabetes (in this case the patient's ethnic origin). Had the diagnosis of gestational diabetes been made, then the birthweight would very likely have been reduced (through improved glycaemic control and planned earlier delivery) and it is very likely that severe fetal hypoxia would have been avoided. A short-term saving for the obstetric unit led to a huge long-term cost in litigation, health and social care, as well as a devastating impact on the mother and her family.

3.2 Pathways to ensuring a high minimum quality of care

National standards for maternity care are produced by several institutions (including NICE and the Royal College of Obstetricians and Gynaecologists (RCOG)), which are intended to reduce local variation in antenatal care. A rolling programme of national audits, co-ordinated via MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK), the National Perinatal Epidemiology Unit and the RCOG, analyses national trends in care provision and adverse outcomes. The ongoing adoption of maternity dashboards to monitor performance is endorsed by the RCOG, allowing units to benchmark their performance against set minimum-quality criteria.

Presently, less than 40% of all trusts belong to a formally organised maternity network with a dedicated co-ordinator – designed to improve utilisation and capacity of services – but 93% of trusts belong to an equivalent neonatal network.¹ Expansion of such a network would also provide scope for a national data collection system with comprehensive and high-quality perinatal outcome data. This would enable both timely central identification of trusts which are outliers against RCOG benchmarking criteria,³⁸ and also allow the efficacy of any new screening tests that are introduced to be evaluated. The largest variation in quality of maternity care arises intrapartum, where the emergency Caesarean section rate varies between 11.3% and 18.1%.¹ The RCOG recommends increased consultant-delivered intrapartum care in an attempt to ensure high-quality provision throughout all maternity services; however, these standards are met by <50% of maternity units.³⁹ In light of evidence suggesting that increased midwifery staffing for women in labour improves maternal outcomes,⁴⁰ midwifery staffing nationwide is an important benchmark of care (see Figure 6.1).

Figure 6.1 Midwife-to-birth ratio, England, 2002 to 2012



Notes

- 1 The births data include a small number of births that took place in, for instance, military and private hospitals, although the midwife numbers at these establishments are not captured in the registered midwives data used here.
- 2 Data on the number of full-time equivalent registered midwives are for 30 September each year and excludes bank staff.

Source: National Audit Office analysis of Health Care Information Centre and Office for National Statistics data

4. Horizon scanning: targeting care through better risk assessment

4.1 The exemplar of pregnancy screening: assessment of Down's syndrome risk

In the 1970s, screening for Down's syndrome was carried out on the basis of maternal age alone, giving a 30% detection rate for 5% false positives. As technology developed in the 1980s, serum biomarkers in the second trimester were added to the screening test, improving the detection rate to 60%–65% at a false positive rate of 5%. Later, screening moved into the first trimester, combining ultrasonic nuchal translucency measurements and new biomarkers to give a detection rate of 85%–95% for <2% false positives.⁴¹ The rate of live births of children with Down's syndrome in the UK has reduced to 54% of expected values.⁴² The future of Down's syndrome screening lies in measuring free fetal DNA in the maternal circulation and initial assessments suggest sensitivity and specificity close to 100%.⁴³

4.2 Placental dysfunction – a case study

A low-risk, 38-year-old nulliparous Caucasian woman presented with reduced fetal movements at 37 weeks. She had accepted all routine antenatal care and screening offered. An ultrasound scan revealed intrauterine fetal death. After induction of labour, an uncomplicated vaginal delivery of a 1.6 kg (<3rd centile for gestational age) stillborn baby girl ensued. Inspection of the placenta demonstrated areas of calcification and infarction. Autopsy and genetic analysis demonstrated that the baby had no structural or chromosomal abnormality. Identification of FGR could have allowed earlier delivery with a very high chance of many years of healthy life gained. Although the societal costs of this case are low, it illustrates an example where relatively modest healthcare expenditure could have led to many years of healthy life gained. This is in contrast to many other areas of medicine where significant expenditure leads to relatively modest reductions in morbidity and mortality.

Currently in the UK, universal screening for FGR is limited to measurement of the size of the uterus with a tape measure, which is known to have a poor detection rate.⁴⁴ Similarly, symphysis fundal height is the primary method of universal screening recommended in the US,⁴⁵ Canada⁴⁶ and New Zealand.⁴⁷

4.3 Screening of low-risk women: benefits and pitfalls

The majority of adverse outcomes, including stillbirths, are not attributable to pre-existing maternal risk factors which can be identified at booking for antenatal care.⁴⁸ For many adverse outcomes in maternity care, including stillbirth, fetal

growth restriction and preterm birth, much of the difficulty in developing screening tests arises from an incomplete understanding of the underlying aetiology.

4.4 Developing new and better screening tests

Gestational diabetes

At present, women are offered screening on the basis of risk factors; however, glucose tolerance testing might be of value for the whole population in the first trimester.⁴⁹ The rationale for earlier testing is, first, that tighter glycaemic control may prevent adverse fetal outcomes,^{50, 51} and, second, that future maternal health may be improved by avoiding hyperglycaemia.⁵² Given that treating gestational diabetes can reduce the incidence of shoulder dystocia by 50%,⁵³ and the average cost of litigation for a single case of shoulder dystocia alone is in excess of £4 million,¹⁹ a universal screening programme could potentially be cost-effective, although a full evaluation would require evidence that the benefits outweighed any risks, and was cost-effective.

Preterm birth

Screening tests for preterm birth exist, such as vaginal swabs to detect fetal fibronectin and ultrasonic measurement of cervical length. Both have limited predictive value in low-risk populations,^{54, 55} but are suitable for use in high-risk populations, eg women with a history of prior preterm birth. Interventions exist which may be effective in reducing the risk of preterm birth, such as vaginal progesterones and cervical cerclage. However, there are limited data from large-scale trials of screening and intervention to prevent preterm birth in low-risk or unselected women.

Placental dysfunction

Two broad approaches to prenatal screening for placental dysfunction have been explored: (1) early pregnancy measurement of biomarkers predicting later dysfunction; and (2) later measurement of fetal growth and Doppler ultrasound blood flow measurements to detect dysfunction that has already occurred. A national evidence-based guideline exists to guide clinical management⁵⁶ – the problem is identifying the at-risk population. A number of first-trimester biomarkers have been described that predict late complications of pregnancy such as FGR and stillbirth.^{57, 58} However, these markers have limited value as screening tests at present due to low positive predictive value. Later in pregnancy, fetal growth is currently assessed via ultrasound in selected women based on risk factors, or assessment of symphysis fundal height in low-risk women. This practice is based on a Cochrane Review which found that 'late pregnancy ultrasound in low-risk or unselected populations does not confer benefit on mother or baby'.⁵⁹ However, a study published in the *Lancet* in 2015 demonstrated that universal screening using ultrasound increased the detection rate of small-for-gestational-age babies three-fold and

identified a fetal growth-restricted group at increased risk of adverse outcomes.⁶⁰ Although numerous screening tests for pre-eclampsia have been studied, in rigorous health economic analysis none of the 27 evaluated tests (either biomarkers or ultrasound indices) was sufficiently accurate to be adopted on a population basis.¹⁴

Complicated first birth

Prediction of intrapartum complications could inform aspects of obstetric care, such as the birth setting, timing and mode of delivery. Up to 45% of women beginning their first labour at home require intrapartum transfer for complications.⁶¹ The ability to screen accurately for likelihood of the risk of complications (such as failure to progress in labour) could lower the rate of transfer. However, no highly discriminatory screening test exists. Induction of labour is a key intervention in the management of fetal and maternal risk.⁶² While recent studies show that induction is associated with reduced likelihood of emergency Caesarean section,^{62, 63} it carries an additional cost (estimated as £190 in a first labour) compared with the spontaneous onset of labour.¹⁷ Improving methods to induce labour, particularly on an outpatient basis, could be a major step towards reducing Caesarean section rates. The current standard of care for intrapartum fetal monitoring is intermittent auscultation of the fetal heart. Continuous electronic monitoring throughout labour reduces the risk of neonatal seizures⁶⁴ but is not universally employed in the UK due to a lack of evidence regarding prevention of other adverse neonatal outcomes.

4.5 Evaluating new screening programs and subsequent interventions

All screening has the potential to increase costs and cause harm. Novel approaches are required to address these methodological challenges. One recent example is a new initiative encompassing both a screening and intervention trial for women with reduced fetal movements in Scotland. The intervention was implemented using a stepped-wedged randomised-controlled trial at the level of obstetric units.⁶⁵ This is a useful future strategy where individual patient-level trials are impractical.

5. Conclusions

Complications of pregnancy carry significant burdens of morbidity, mortality and cost, both immediately and in the longer-term. The majority of adverse outcomes that occur in women are not related to known risk factors. Screening and intervening to prevent these outcomes present enormous challenges, but also enormous opportunities. Finally, the consequences of adverse outcomes, in terms of litigation and lifelong consequences for families are profound. Dissociation between provision of care and the management of the consequences of its failure is widespread. This can lead to short-term and modest economies leading to long-term and substantial societal burdens. Better feedback from agencies dealing with, say, litigation to both providers and commissioners of care may have beneficial effects on the total societal burden caused by pregnancy complications.

6. Authors' key messages for policy

- The consequences of failures of maternity care are associated with increased costs in the short, medium and long term; therefore, spending on maternity care should be maintained or enhanced.
- Currently, research into the causes, prevention and treatment of complications of the second half of pregnancy are not prioritised by the Medical Research Council. Pregnancy complications should be identified as a high priority for UK government research funding.
- Specific cases have arisen where provision of care has failed in some trusts, leading to higher rates of severe adverse events. However, there is no national data collection system that allows identification of outliers, due to the lack of comprehensive, high-quality and complete maternity outcomes data in England. Creation of such a database should be prioritised. As well as facilitating audit, with appropriate permissions it could be a powerful resource for research.

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Chapter 7

Perinatal mental health

Chapter lead

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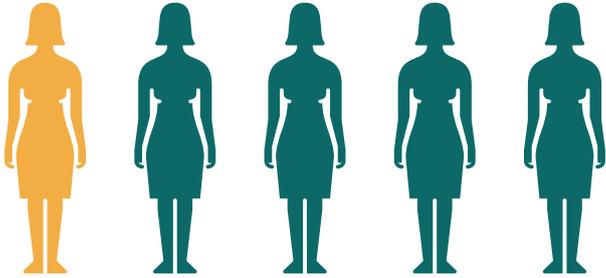
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Perinatal mental health



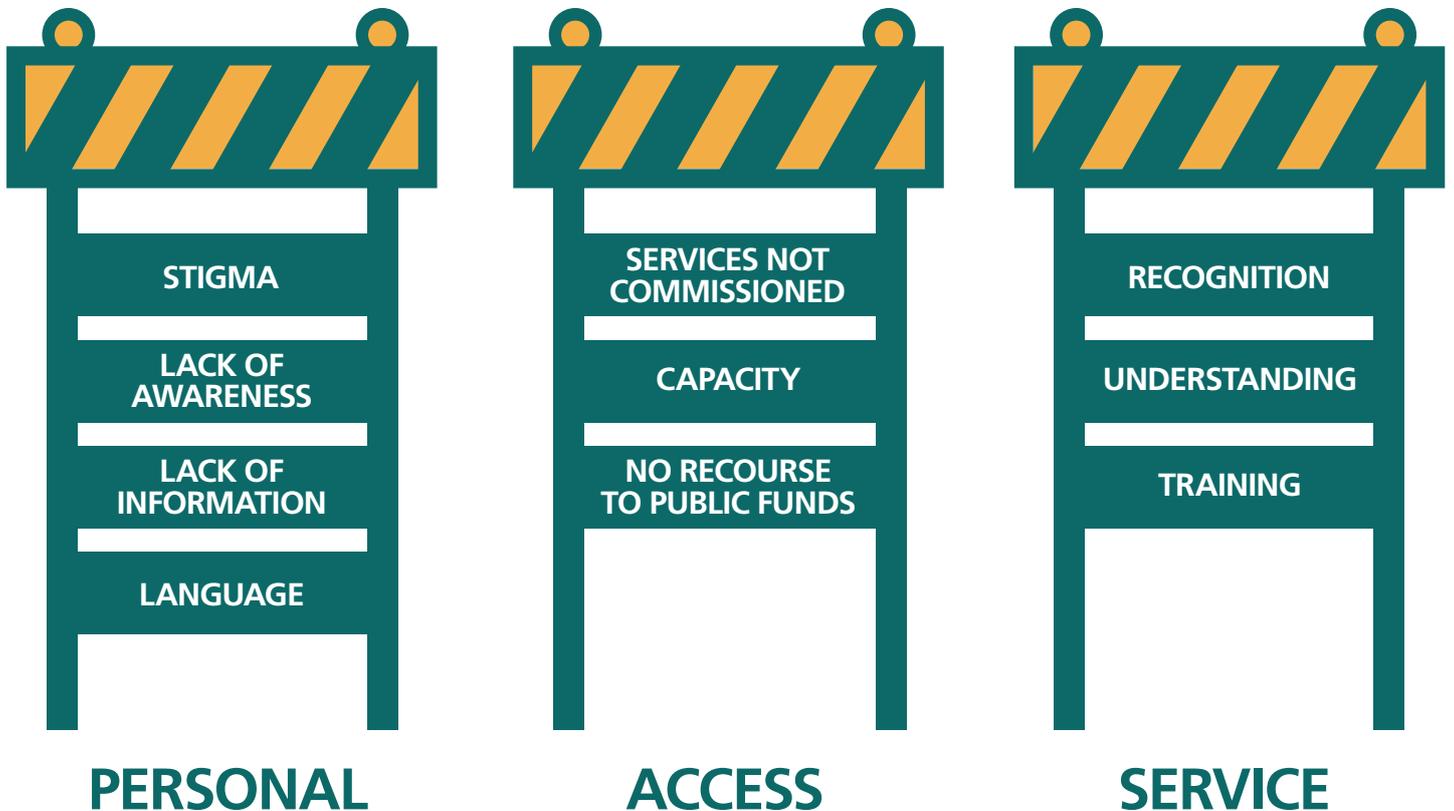
1 in 5 women

DEVELOP A MENTAL ILLNESS DURING PREGNANCY OR IN THE YEAR AFTER BIRTH

£8.1 billion

THE DIRECT AND INDIRECT COSTS OF PERINATAL MENTAL ILLNESS FOR EACH ANNUAL COHORT OF BIRTHS IN THE UK

BARRIERS TO BETTER OUTCOMES IN PERINATAL MENTAL HEALTH



1. Key statistics

- Perinatal mental illnesses are very common, affecting 1 in 5 women at some point during the perinatal period (during pregnancy and the first year after birth).
- Perinatal mental illness can have a devastating impact, the all cause mortality for these women is 21.6 per 100 000 pregnancies, during pregnancy and the year after delivery.
- Perinatal mental illnesses are associated with risks of negative child outcomes, which can persist into late adolescence and adulthood. However, these risks are more likely in children of women with chronic mental illness or who are living in poverty.
- Perinatal mental health services are inequitably distributed in England; only 3% of Clinical Commissioning Groups have a strategy for commissioning specialist perinatal mental health services, despite women in nearly half of the UK having little or no access to specialist perinatal mental health services.

2. Overview

Mental illness is among the most common morbidities of childbearing.¹ It is estimated that 1 in 5 women will develop a mental illness during pregnancy or in the year after birth. Help is not easily available as many health professionals lack knowledge about perinatal mental health, and there is limited availability of specialist services that are tailored to women's mental health needs during pregnancy and postpartum,² in contrast to the availability of specialist physical health services (for example for diabetes) during pregnancy. If left untreated, mental illnesses are associated with significant long-term implications for the health of the women, their children, families and wider society.^{3, 4}

The Maternal Mental Health Alliance will produce updated maps of pertinent services for women in December 2015. Please see <http://maternalmentalhealthalliance.org.uk/>

3. Epidemiology

Depression and anxiety are the most common mental illnesses in pregnancy and the year after childbirth ('the perinatal period'), with 20% of women experiencing symptoms of mental illness at some point during this period.^{1,5} There is debate as to whether there is a peak in the incidence (ie new onset cases) of depression in the postnatal period, compared with other times in a woman's life.¹ One US study reported that around half the cases of 'postnatal depression' identified had actually started earlier (ie during or before pregnancy)⁶ and identification of depression may be easier after childbirth when there are many contacts with professionals for both the mother and her baby. However, longitudinal studies using medical records and data on admissions for severe depression suggest that there is an increase in the incidence (new cases) of depression after childbirth compared with the period before pregnancy, during pregnancy or after the first postnatal year.^{7,8}

Anxiety is often also prevalent,⁹ with generalised anxiety disorder being the commonest type of anxiety disorder. Other illnesses which can occur include obsessive–compulsive disorder, post-traumatic stress disorder (PTSD) and tokophobia (extreme fear of giving birth).⁵ The prevalence of binge eating disorder was found to be higher during pregnancy in a Brazilian cohort¹⁰ but the prevalence of anorexia nervosa, bulimia nervosa and other eating disorders is lower.^{11,12} There is little research on personality disorder in the perinatal period, but one Swedish study suggests a prevalence of 6% in pregnancy¹³ and associations with worse mental health¹³ and child mental health outcomes.¹⁴

Importantly, the perinatal period is associated with increased risk of severe mental illnesses¹⁵ compared with both pre-pregnancy and after the first year after birth. A relapse of severe mental illness, or onset in the perinatal period, can lead to severe psychological morbidity, an inability to care for the infant and other members of the family, rarely suicide, and (more rarely) infanticide.^{15,16} Postpartum psychosis – severe episodes of mood disorder which develop quickly in the early postpartum period – affects around 1 in 1,000 women¹⁵ who have given birth and usually requires admission, ideally to a specialised psychiatric Mother and Baby Unit. Women with a history of bipolar disorder are at particular risk – 20% of mothers with bipolar disorder have a postpartum psychosis,¹⁷ but it can also occur in women with no previous psychiatric history.⁷ Women with psychotic illnesses such as schizophrenia or bipolar disorder are also at risk of relapse throughout the perinatal period if they stop prophylactic medication or experience stressors that are associated with risk of relapse.¹⁵

4. Aetiology of perinatal mental illnesses

Previous traumatic experiences, low support and limited information from healthcare staff during childbirth^{18,19} and obstetric complications have been implicated in the development of PTSD after childbirth.¹⁹ However, most perinatal mental illnesses have causes that are similar to mental illnesses at other times in a woman's life. These include genetic factors, a history of mental illness, low socio-economic status, migration status, poor or no partner support^{20,21} and a history of childhood or adulthood abuse.¹ Hence many of the risk factors reflect well-established social determinants of health.

5. Impact

Perinatal mental illness is associated with long-term psychiatric morbidity so that around 30% of women diagnosed with postnatal depression still have depression beyond the first year after childbirth²² and a significant proportion of women who experience perinatal depression and/or anxiety will develop recurrent long-term mental illnesses.⁴

The human cost of perinatal mental illness has tragically been illustrated by the triennial Confidential Enquiries into Maternal Deaths. Over the last 15 years, since psychiatric causes of death were included, these reports have shown that suicide is one of the leading causes of maternal death in the UK.^{23, 24} The Confidential Enquiries have been a great driver for reducing maternal mortality but, although there has been a reduction in mortality from physical causes such as haemorrhage, deaths due to psychiatric causes have not fallen.²⁴ Furthermore, sampled data from the Clinical Practice and Research Datalink covering the period 2007 – 2014 showed that all-cause mortality rates for women with mental illness during pregnancy and up to 12 months postpartum was 31.14 deaths/100 000 pregnancies (95%CI 10.01-72.30), around 2 fold higher than those reported in women without a record of mental health illness recorded in the same period.²⁵

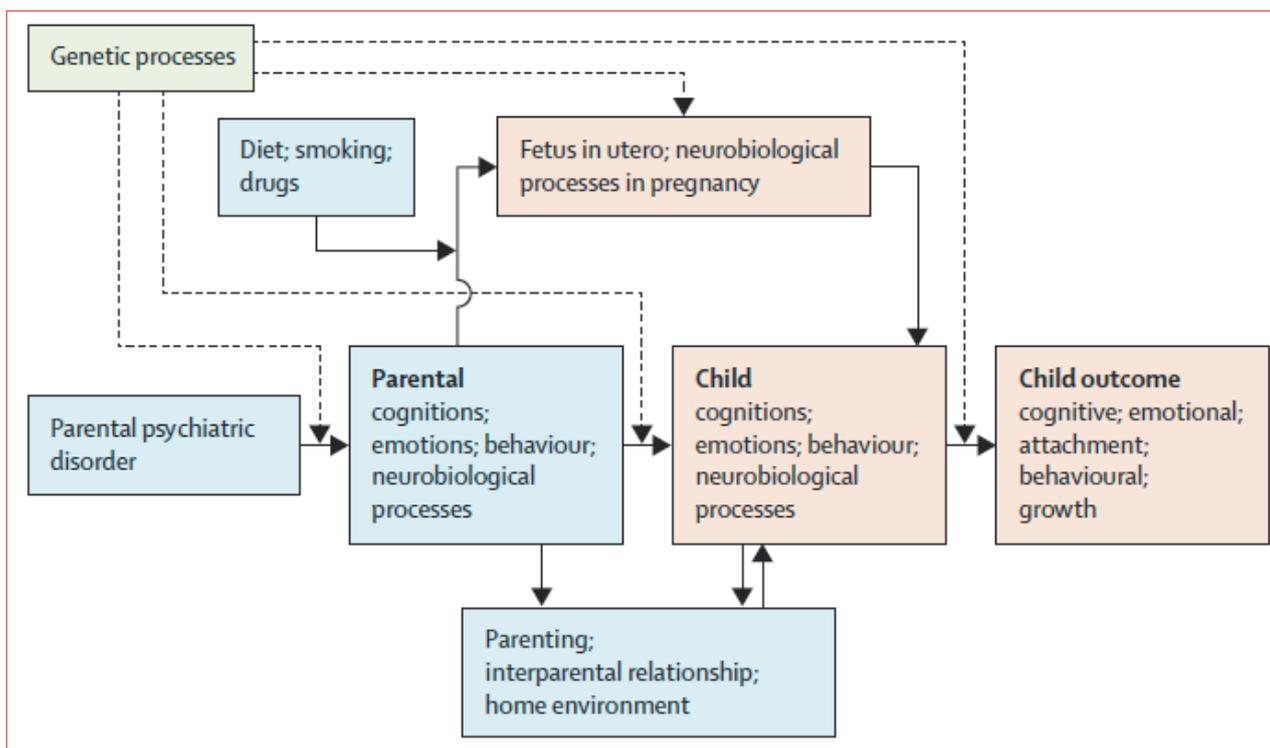
There is a growing evidence base on associated negative outcomes for the fetus and child³ which include increased

risk of premature delivery (<37 weeks' gestation), child emotional problems, externalising disorders in childhood, insecure attachment and lower levels of general cognitive development.³ Important moderating factors include low socio-economic status^{26, 27} and the education level of the mother,²⁸ low social and emotional support²⁹ and/or persistent chronic maternal depression.³ Co-morbidities commonly associated with perinatal mental illnesses, such as domestic violence,³⁰ obesity³¹ and smoking³ can accentuate the risk of poor obstetric and longer-term adverse outcomes for both mother and child. The research literature and the media have a long history of focusing on how women's behaviours and symptoms affect their offspring – this 'mother blaming culture' does not address these complex social problems and could harm women further.

Recent modelling of the economic cost of perinatal mental illness suggests that each annual cohort of births in the UK is associated with a cost of £8.1 billion, with 72% of this cost related to infant and childhood morbidity and mortality. Over a fifth of total costs are borne by the public sector with the bulk of these falling on the NHS and social services.²

Deficits in maternal–infant interactions are key mediators in the relationship between postnatal illnesses and adverse child cognitive, behavioural and emotional outcomes, but there is limited research on the effectiveness of interventions to address these deficits in women with perinatal mental illness.^{3, 5}

Figure 7.1 Possible mechanisms underlying the association of parental psychiatric disorders and child outcomes



Red surrounding line indicates socio-economic factors which have influence on all other mechanisms. Dotted lines show genetic processes. Solid lines show interactions. Orange colours refer to the child. Blue colours refer to the parents. Green represents genetic processes.

Source Adapted from Figure 1, Stein A et al. Effects of perinatal mental disorders on the fetus and child. The Lancet. 2014

6. Treatment

The National Institute for Health and Care Excellence (NICE) (2014) recommends a stepped care approach in the treatment of perinatal mental illnesses with the majority being supported and treated in primary care by GPs, midwives, health visitors and primary care psychological therapy services (also known as IAPT – Improving Access to Psychological Therapies). Women with more severe illnesses should be treated in secondary care.

NICE and the Confidential Enquiries into Maternal Deaths highlight the opportunity to optimise outcomes by pre-conception counselling. This allows general interventions such as smoking cessation to be offered and the opportunity to plan how any existing physical and mental illnesses can be managed in pregnancy, in order to optimise pregnancy outcomes. NICE (2014) recommends that all health professionals in contact with women of childbearing age who have current, or a history of, mental illness should offer, or refer them for, pre-conception advice. There is evidence from the Confidential Enquiries into Maternal Deaths that many of the women who died as a result of mental illness required different management and/or specialised services during pregnancy, but did not receive any pre-pregnancy counselling or specific individualised perinatal mental health advice.²⁴ It is estimated that in 52% of cases improvements to care, such as extra supervision and care within a perinatal care plan, may have made a difference to outcomes.²⁴

In addition, professionals in contact with pregnant women need to be able to identify women with possible mental illnesses, and refer them appropriately for assessment and treatment.^{5, 33} Evidence-based effective interventions for mental illnesses and associated risk factors are available and include psychosocial interventions, psychological therapies and psychotropic medication.^{1, 5, 15, 32, 34} However, the threshold for pharmacological interventions is higher during pregnancy and breastfeeding due to the uncertainty regarding possible risks to the fetus and nursed infant, and psychological therapies should therefore be first line treatment for most women presenting with mild or moderate illnesses.⁵

Discussions regarding medication for women of childbearing age need to include information and advice on whether the medication is potentially problematic for a future pregnancy. Sampled CPRD data analysed for this report found that prescribing SSRI antidepressants in pregnancy has significantly increased over time (2007-14) with most recent estimates of 5573.05 (95%CI 5234.71-5925.79) per 100 000 pregnancies.³⁵ Children exposed *in utero* to valproate are at a high risk of significant neurodevelopmental problems (in 30–40% of cases) and/or congenital malformations (in approximately 10% of cases). However, data from the Clinical Practice Research Datalink suggest that approximately 35,000 women aged 14 to 45 a year had a prescription for sodium valproate between 2010 and 2012. Of these, at least 375 a year had a prescription for sodium valproate while pregnant.³⁵

Although the majority of the prescriptions were for epilepsy, some are clearly being used as mood stabilisers and there is evidence that NICE guidance is also not being followed by mental health professionals.^{5, 36} The NICE guidance⁵ and a recent Medicines and Healthcare products Regulatory Agency (MHRA) drug safety update³⁶ recommend that valproate should not be prescribed to women who are pregnant or of childbearing potential for acute or long-term treatment of a mental health problem.

NICE recommends that pregnant women with suspected or known severe mental illness should be referred to a secondary mental health service, preferably a specialist perinatal mental health service, for assessment and treatment.³⁷ Specialist perinatal mental health services provide expert advice on the risks and benefits of psychotropic medication treatment or prophylaxis for mental illness during pregnancy and breastfeeding. Inpatient Mother and Baby Units are in place, though with some regional gaps in provision, for women needing psychiatric admission to promote recovery of the mother and help her with her relationship with the baby.⁵ It is concerning that, despite the risk of relapse with potentially devastating consequences for women with severe mental illness,^{38, 39} pregnancy is a major reason for medication discontinuation^{37, 40, 41} and women are far more likely to discontinue psychotropic medication suddenly if it is prescribed for a severe mental illness than if the same medication is prescribed for a serious physical illness such as epilepsy.⁴¹

7. Service response

Perinatal mental illnesses are poorly recognised and understood by maternity and primary care health professionals, despite frequent contact in the perinatal period by maternity care, primary care and health visiting services.⁵ Training of professionals in contact with pregnant women and mothers often fails to include perinatal mental health, or focuses only on postnatal depression. In a recent survey of GPs, 40% said that they had never had any specific teaching on perinatal mental health during their careers.⁴² CPRD data analysed for this report indicates substantial under-recording (so presumably under-identification) of perinatal mental disorders in primary care – during the period when the GP Quality Outcomes Framework asked GPs to use screening tools for depression, rates recorded were only around 25/100 pregnancies (2007-9) (epidemiological studies would suggest this should be 4 times higher), and more recently significantly fewer have been recorded eg in 2014/15 only 5.96/1000 (95%CI 4.81-7.14).⁴³ The identification of mental illness in pregnancy and postpartum has only recently been highlighted as a core competency for both obstetricians and midwives.⁴⁴ The Royal College of Psychiatrists' Faculty of Perinatal Psychiatry Executive has raised concerns about the lack of training in perinatal mental health for general psychiatrists and the lack of recognised specialty training for those wishing to specialise in perinatal psychiatry.⁴⁵ The lack of a perinatal specifier (ie whether a woman is pregnant or has had a child in the last year) in the Minimum Mental Health Dataset has also contributed to difficulties in mental health service awareness of this group and therefore development of services to meet the particular needs of this group.

Acknowledging this problem, the recent Health Education England mandate⁴⁶ highlights work with the Nursing and Midwifery Council and the Royal College of Midwives to ensure that midwives in training have a core training module focusing on perinatal mental health. The mandate also commissions future development of a continuing professional education framework for the existing maternity and early years workforce, and work with the relevant medical colleges to support specific perinatal mental health training being incorporated into the syllabus for doctors in postgraduate training.⁴⁶ At present the Royal College of Obstetricians and Gynaecologists is addressing perinatal mental health by making changes in its curriculum for postgraduate exams. In addition, a multi-agency training package written by the Institute of Health Visiting has been delivering scheduled training sessions for (predominantly health visitor) Perinatal Champions and Maternity Perinatal Champions.⁴⁷

Women value good co-ordination and communication between health professionals^{48, 49} and NICE guidance highlights the need for co-ordinated care and the development of an integrated care plan for women with perinatal mental illnesses.³⁴ However, too often this is not the experience offered by services: women commonly report that fragmented provision of healthcare has contributed to

their emotional isolation^{46, 50-52} and difficulties in sharing their worries and anxieties during pregnancy.⁴⁸ In addition, as highlighted in several independent inquiries into the deaths of mothers who took their own lives,^{53, 54} women who are at risk of relapse of a severe mental illness but are well when seen in pregnancy are often expected to know when and how to contact services, rather than the responsibility being held across services with the family. Many health professionals were unaware of the increased postpartum risk of severe mental illness.²⁶ Problems with the referral process and access to perinatal mental health services, the disparity in professional appreciation of the severity of symptoms, and issues with continuity of care and follow-up (especially in women who did not attend maternity appointments or were not at their address for midwifery postnatal visits) have also been highlighted.⁵⁵

8. Access to services

There is a patchy service with little or no specialist perinatal mental health provision in large parts of the country:^{2, 56} in almost half of the UK, women and their families do not have access to specialist perinatal mental health services.² It has also recently been reported that just 3% of Clinical Commissioning Groups (CCGs) in England have a strategy for commissioning perinatal mental health services and that a large majority have no plans to develop one.⁵⁷

Recent NHS England guidance on new mental health access and waiting time standards for 2015/16 state that 75% of people referred to the Improved Access to Psychological Therapies programme should be treated within 6 weeks of referral, and 95% within 18 weeks of referral.⁵⁸ NICE CG192 recommends particularly prompt access to treatment for pregnant and postpartum women.⁵ However, currently there is a lack of both capacity and of perinatally competent staff within services.³⁴

Access to services is also problematic for specific groups. Black Caribbean women are less likely to receive treatment for perinatal depression than their white British counterparts.⁵⁹ Postnatal depression is more common in migrant (refugee, asylum seeking, immigrant) women when compared with native born women.^{60, 61} This is of considerable importance given the growing numbers of babies born to women who have recently migrated to the UK; indeed, the proportion of births in England and Wales to non-UK born women increased from 16% in 2001 to 26% in 2011.⁶² These women are not a homogenous group and have individual risk factors. Factors that affect levels of depression include low social support, life events and social adjustment as well as cultural postpartum issues, and language and communication difficulties.^{60, 62} Barriers to seeking help also include having no recourse to public funds, or being a victim of human trafficking,⁶³ or dispersal of asylum seekers or refused asylum seekers (as those requiring support and accommodation may be sent anywhere in the UK).⁶⁴

9. Stigma

The stigma surrounding mental illness exacerbates women's problems by preventing them from being open about their worries and seeking the help they need.⁶⁵ Many women worry that having a mental illness is not perceived as compatible with being a good mother and represents a sign of failure.^{65, 66} Women with mental illnesses struggle with feelings of shame and fear that the baby may be taken away and, as a result, may choose not to disclose their feelings, leading potentially to untreated and worsening symptoms.^{64–66} Even more worrying is that discrimination and ignorance are also common among health professionals, with women reporting that health professionals are often too busy or unwilling to listen to them and are judgemental and dismissive of attempts to communicate emotional distress.⁶⁷

Parents with mental illness also experience stigma from children's services and the legal system where their pathology is emphasised rather than their parenting abilities.^{68–71} Many studies have found that the public views people with mental illness as responsible for their disorders and believes that they are to blame for the symptoms and disabilities that result.⁷² Parents with severe mental illness such as schizophrenia or bipolar disorder experience stigma from mental health professionals and are rarely asked about parenting or helped to access parenting support.⁷³ Mothers are more likely than fathers to perceive and internalise stigma associated with the impact of their mental illness on their parenting.⁷⁴

To date, most large-scale anti-stigma campaigns have not included perinatal mental health, despite evidence that women anticipate more discrimination than men around being a parent with mental illness.⁷⁵ Improvements in public attitudes and intended behaviour have been observed over the course of the latest national anti-stigma campaign (Time To Change).⁷⁶ However, although the actual reported experience of discrimination has fallen, there has been no change in how patients anticipate that they will experience discrimination.⁷⁷ It remains to be seen whether these anti-stigma programmes can impact on women's fears.

10. Public awareness

Information available to the public has traditionally focused on postnatal depression and many women complain of a lack of information on other perinatal mental illnesses.^{47, 78, 79} In addition, although there are several decision tools for physical health interventions such as Caesarean section in pregnancy,⁸⁰ there are no such tools for mental health interventions such as psychotropic medication.⁸¹ The media may aggravate women's anxieties by publishing alarming truncated accounts of scientific research. One Canadian study⁸² examined the impact of a drug safety update on the potential adverse effects of antidepressants on newborns and its subsequent reporting in the media. Women taking an antidepressant called a national helpline and all reported anxiety, with some discontinuing antidepressants (some abruptly) without a clear risk–benefit analysis discussion with accurate information from a health professional.

Resources have, however, been developed by statutory and professional bodies – for example, the Royal College of Psychiatrists' leaflets on mental health in pregnancy and postpartum psychosis⁸³ and NICE CG192 information for the public.⁸⁴ The UK Teratology Information Service (UKTIS) provides a national service on all aspects of the toxicity of drugs and chemicals in pregnancy, with information provided for health professionals and women online.⁸⁵ Relevant charities have also developed resources – for example, Action on Postpartum Psychosis has produced a series of guides on the disorder with the help of women who have experienced postpartum psychosis and their partners,⁸⁶ and the National Centre for Mental Health in Wales in conjunction with Action on Postpartum Psychosis (APP) and Bipolar UK have developed a leaflet on bipolar disorder, pregnancy and childbirth.⁸⁷

11. Conclusion

Mental illnesses are the commonest morbidities of the perinatal period¹ and are associated with significant long-term psychiatric morbidity and mortality.²⁵ There is also a growing evidence base of associated negative outcomes for the child³ and a significant financial burden for society.² Evidence-based effective interventions are available but health professionals' lack of perinatal mental health knowledge⁴¹ and difficulties in identification of risks before women become pregnant lead to missed opportunities for intervention. The stigma surrounding perinatal mental illnesses may prevent women from seeking help⁶⁵ and media misinformation fuels anxiety around treatment.⁸² The lack of comprehensive information for women may also compound this problem. Furthermore, there are many areas of the country with no access to specialist services² and, despite this, only a minority of CCGs have a strategy for commissioning perinatal mental health services.⁵⁶ It has been suggested that, in order to address the significant burden of perinatal mental illnesses, wide-ranging changes in society's perceptions of the problem, training of health professionals and commissioning of service provision will be required.³³ NICE guidance⁵ and commissioning guidance³³ set out what high-quality care should look like, but in some areas there are few or no integrated care pathways involving adequately trained, competent staff, or specialist services. It is clear that, if existing guidance was implemented, high-quality care could be provided.

12. Authors' suggestions for policy

- Reduce stigma. Include perinatal mental health stigma in anti-stigma campaigns and target schools, children's centres and maternity services to address women's fears. Support and evaluate such programmes.
- Train all health professionals in contact with women in the perinatal period to identify and treat, or refer for treatment, women with perinatal mental illnesses in accordance with NICE guidance.
- Primary and secondary mental health care professionals need to provide, or refer appropriately for, pre-pregnancy advice for childbearing aged women with a past, current or new mental illness.
- Education providers should ensure that health professionals in contact with pregnant and/or postpartum women (eg in primary care including psychological therapy services, maternity care, secondary community and inpatient mental health services) have perinatal competencies included within training curricula.
- NHS England and Clinical Commissioning Groups should ensure that women in all parts of England have access to specialist perinatal mental health services, both inpatient Mother and Baby Units and perinatal mental health community teams.
- Develop decision aids to help clinicians and women with complex decisions relating to the management of perinatal mental illnesses such as medication in pregnancy.
- Universal resources should integrate information about physical and mental health, thus potentially de-stigmatising mental illnesses, while also providing a range of information.
- Professionals need to be aware of cultural differences and health inequalities and how these may impact on the risk of developing a perinatal mental disorder and accessing services.
- Develop referral and care pathways that ensure timely assessment and treatment for women with or at risk of severe mental illness.
- Ensure that women with the whole range of mental health problems (including personality disorders) in pregnancy and postnatally have NICE-compliant access to psychological therapies. Create a service development perinatal work stream within Improving Access to Psychological Therapies (IAPT), similar to the ones created for old age or children and young people.
- Ensure that all women with, or at risk of, perinatal mental illnesses have an integrated care plan, and promote good integrated care pathways involving all relevant agencies, the women and their families.

Case Study – London Perinatal Mental Health Network

Due to patchy, varying quality and inequitable provision of perinatal mental health services in London, a joint Mental Health and Maternity Services Workshop decided in January 2013 that a Pan London Network would be developed to agree common structures and processes for the organisation and delivery of perinatal mental healthcare at Tiers 1–4. Modest funding from NHS London enabled a Network Coordinator to be seconded for one day a week, supported by a steering group and three Perinatal Mental Health Clinical Networks for North East, North West and South London. The networks are aligned with the three psychiatric Mother and Baby Units; 10 Mental Health Trusts; six Maternity Networks; 32 Clinical Commissioning Groups; three Local Education Training Boards; and three Academic Health Sciences Centres. The chairs of the three Perinatal Mental Health Clinical Networks sit on the Pan London Perinatal Mental Health Network so that they can report on the progress of the Networks, which all have the same priorities. Over 160 people from a variety of organisations have joined the Networks to date, including representatives from perinatal and parent infant mental health services; midwifery; obstetrics; health visiting; social care; the third sector; service users; and commissioners. The London Perinatal Mental Health Networks are accountable to the Clinical Director of the London Mental Health Strategic Clinical Network (SCN) and are supported by the London Maternity SCN and the London Children's SCN.

The London Perinatal Mental Health Networks' priorities were:

- To develop standardised London-wide perinatal mental health training. Health Education North Central and East London (HENCEL) funded the development of comprehensive tiered training and education packages (by the end of March 2015) and in total around 1,000 training sessions will be offered.
- To develop a London Perinatal Mental Health Care Pathway and standard protocols. A Pan London Mother and Baby Unit admission protocol had already been developed and circulated among commissioners. A draft care pathway is currently out for consultation.
- To undertake a Pan London Perinatal Mental Health Needs Assessment. The Network has developed a database detailing service provision and gaps in 32 boroughs.
- To develop a London perinatal information-sharing 'Electronic Hub'. Information will be held on the Royal College of Psychiatrists' website in the Perinatal Quality Network area.

In addition, two conferences have been held with over 250 participants and the Pan London Network and the three Clinical Networks have met regularly every three months. As a result of the work of the Network, London Mental Health SCN has made perinatal mental health one of its key priorities for 2015/16. This will be driven by the Mental Health Transformation Board, who will be able to influence all the CCGs in relation to perinatal mental health and will give authority to the agreement of a London commissioning pathway.

13. Glossary

Term	Definition
Adjustment disorder	An adjustment disorder is characterised by the development of emotional or behavioural symptoms in response to an identifiable stressor (or stressors) occurring within three months of the onset of the stressor. A stressor is anything that causes a great deal of stress in the person's life. The stress-related disturbance does not meet the criteria for another specific mental disorder.
Anxiety disorders	Disorders characterised by anxiety. Generalised anxiety disorder is the commonest of the anxiety disorders and is characterised by excessive worry about a number of different events, associated with heightened tension. For the disorder to be diagnosed, symptoms should be present for at least six months and should cause clinically significant distress or impairment in social, occupational or other important areas of functioning. Other anxiety disorders include phobias, panic disorder, obsessive–compulsive disorder and body dysmorphic disorder.
Bipolar disorder	A mood disorder characterised by episodes of mania (abnormally elevated mood or irritability and related symptoms with severe functional impairment or psychotic symptoms) or hypomania (abnormally elevated mood or irritability and related symptoms with decreased or increased function) and episodes of depressed mood.
Common mental disorders	This term refers to anxiety disorders and depression.
Depression	Both the International Classification of Diseases (ICD) (World Health Organization) and the Diagnostic and Statistical Manual of Mental Disorders (DSM) (US) diagnostic systems require at least one (DSM-IV) or two (ICD-10) key symptoms (low mood, loss of interest and pleasure or loss of energy) to be present. Severity of the disorder is determined by both the number and severity of symptoms, as well as the degree of functional impairment. Formal diagnosis using the ICD-10 classification system requires at least four out of ten depressive symptoms, whereas the DSM-IV system requires at least five out of nine for a diagnosis of major depression (referred to in this chapter as 'depression'). Symptoms should be present for at least two weeks and each symptom should be present at sufficient severity for most of every day.
Direct causes of death	Term used in the Confidential Enquiries into Maternal Deaths in the UK to describe medical conditions that could only be the result of pregnancy such as obstetric haemorrhage.
Indirect causes of death	Term used in the Confidential Enquiries into Maternal Deaths in the UK to describe pre-existing or new medical or mental health conditions aggravated by pregnancy/postpartum period.
Mental illness	A clinically recognisable set of symptoms or behaviour associated in most cases with distress and with interference with personal functions.
Perinatal period	The period spanning pregnancy and the year after birth.
Postpartum	The year after birth.
Postpartum psychosis	Severe mental illness of sudden onset in the postpartum period, characterised by mood disturbance (mania and/or depression) and psychotic symptoms such as hallucinations or delusions.
Psychiatric causes of death	Term used in the Confidential Enquiries into Maternal Deaths to describe deaths that arise directly from a mental health disorder, suicide or accidental overdose of drugs of abuse, as well as deaths from medical or other causes that are closely related. The latter include physical consequences of substance misuse and delays in diagnosis, and treatment because of the presence or assumption of a mental disorder, accidents and violence.

Term	Definition
Psychotic disorder	A mental illness characterised by symptoms such as hallucinations, delusions and disordered thinking, eg schizophrenia.
Psychotic symptoms	Include hallucinations and delusions.
Serious mental illness (SMI)	Includes schizophrenia and bipolar disorder but any illness involving severe symptoms may be included.
Tokophobia	Anxiety disorder characterised by extreme fear of childbirth.

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Chapter 8

Post-pregnancy care: missed opportunities during the reproductive years

Chapter lead

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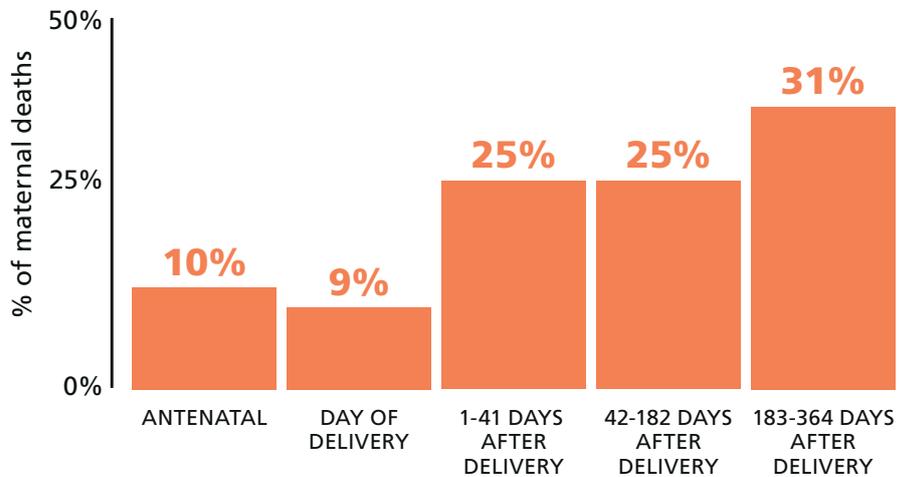
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Post-pregnancy care

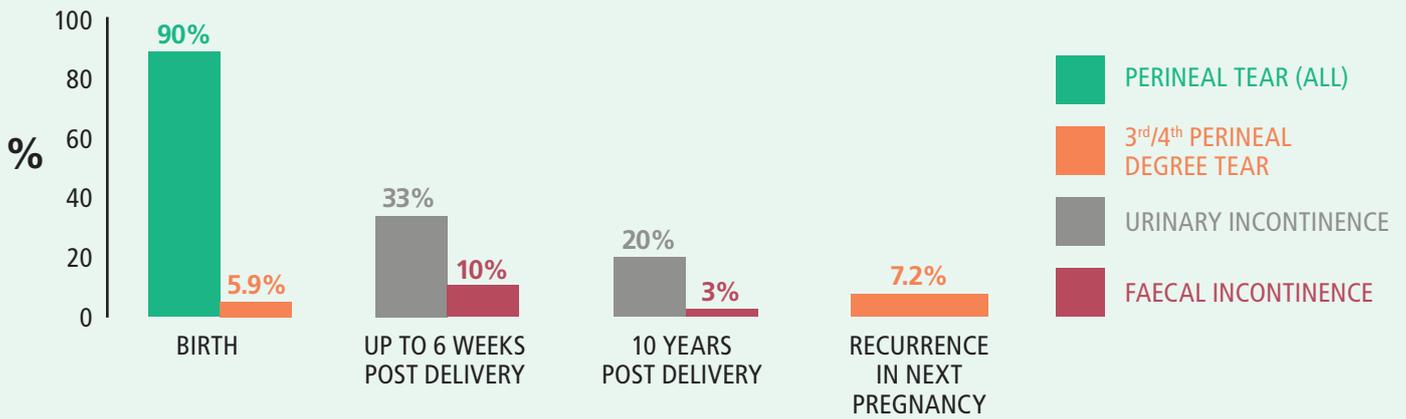
90%
OF MATERNAL DEATHS OCCUR POST DELIVERY

973 MATERNAL DEATHS IN THE UK DURING AND AFTER PREGNANCY, 2009-13

TIMING OF MATERNAL DEATHS 2009-2013



MORBIDITY AFTER PREGNANCY



BREAST FEEDING

BREASTFEEDING IS ASSOCIATED WITH:

MOTHER

Lower post-partum weight retention
Delays resumption of periods

BABY

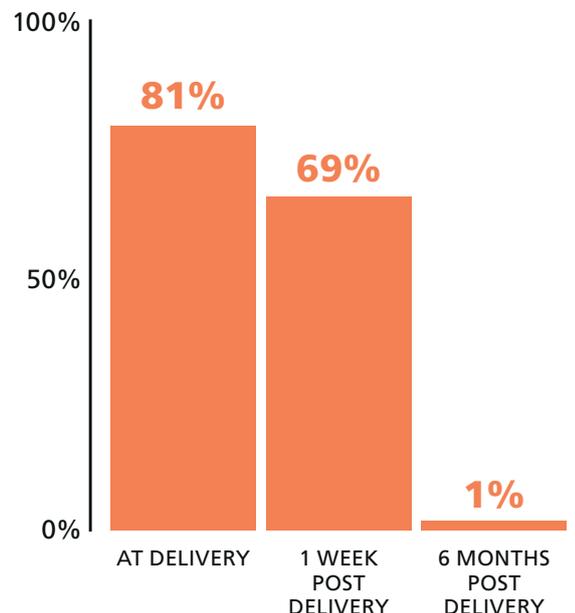
Lower rates of

- gastroenteritis
- sudden infant death syndrome
- respiratory disease

Better cognitive development
Fewer behavioural problems



% EXCLUSIVELY BREAST FEEDING:



1. Key statistics

- There were 646,904 deliveries in England during the financial year 2013/14. Some 69.2% of delivery episodes had a total inpatient stay of ≤ 2 days.
- In 2013/14, 8.3% of Asian and Asian British women had infants of low birth weight compared with 6.3% of black and black British women and 5.1% of white women.
- Three-quarters of women who died during or within the first 6 weeks after pregnancy in 2009–12 had pre-existing physical or mental health problems.
- Perinatal mental illness in the UK is estimated to carry costs to society of around £8.1 billion for each one-year cohort of births.
- 90% of 4,571 women who completed a UK-wide survey of experiences of maternity care received a GP postnatal check 4 to 8 weeks after birth.
- In 2010, in England, the prevalence of breastfeeding was 81% at birth, falling to 69% at one week. Only 1% of women were exclusively breastfeeding at 6 months.
- Analysis of all deaths of women during pregnancy or in the year after the end of pregnancy in 2009–13 found that 325 (34%) of 971 maternal deaths occurred within 6 weeks of birth and 547 (56%) after 6 weeks and up to 12 months post birth.

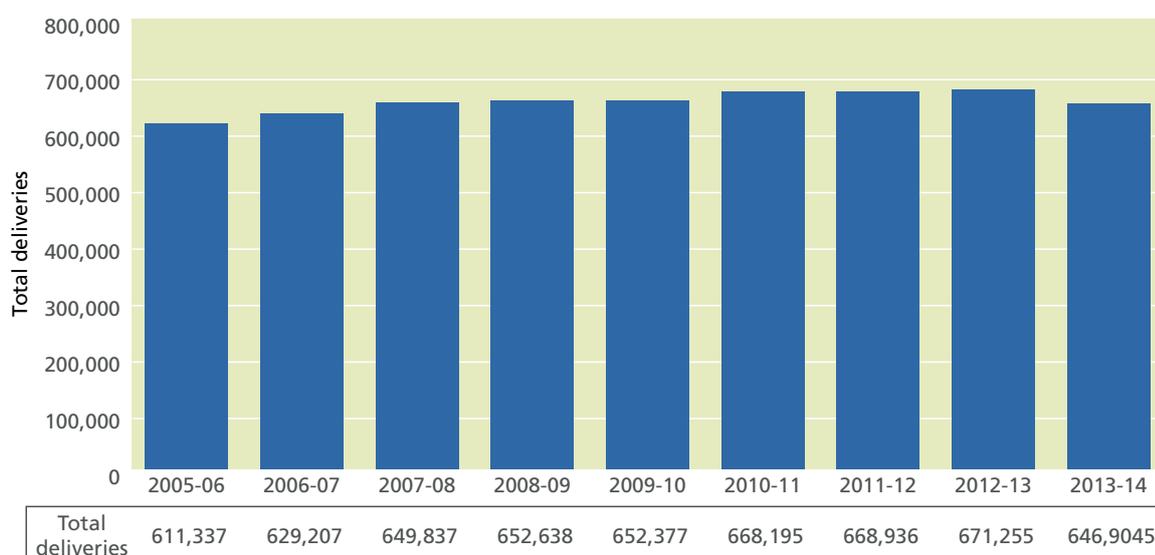
2. Overview

Postnatal care is usually concluded by 6–8 weeks post birth, which marks the formal end of maternity care in England.¹ The aim of care is to enhance birth recovery, promote maternal and infant physical and psychological health, and support infant feeding.¹ The current timing and content of postnatal care originated in the early 20th century in response to the then high maternal mortality rate. It has since been subject to minimal revision, despite a dramatic decline in maternal mortality, increasingly early postnatal discharge, and evidence of widespread and persistent maternal morbidity.² The health profile of women giving birth in 2015, including older age at first pregnancy, increased use of Assisted Reproductive Technology (ART), and higher prevalence of obesity and other medical complications^{3,4} is not reflected in postnatal care provision. The authors consider that current postnatal care is not fit for purpose, lacking any basis in either evidence or maternal need.

The number of deliveries in England increased over the last decade, apart from a small decline in 2013/14 (Figure 8.1).

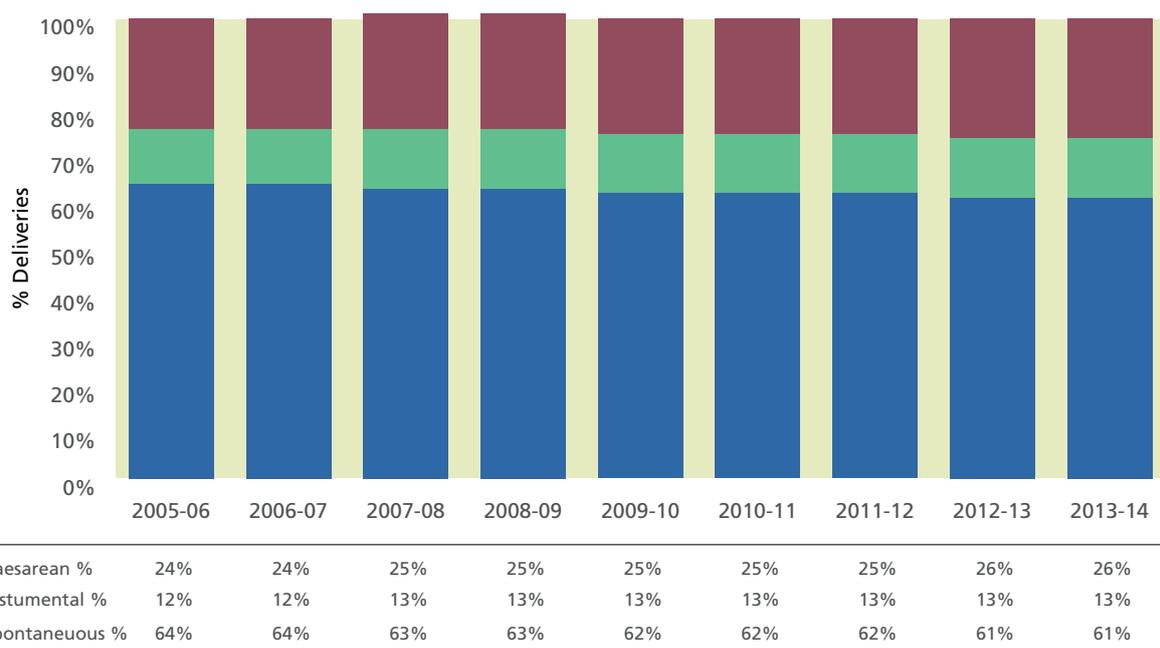
Over the same period Caesarean section deliveries increased from 23.5% to 26.2%³ (Figure 2). Maternal factors such as being obese or overweight, older age and conditions such as diabetes or hypertensive disorders increase both the risk of intervention^{5,6,7} and longer-term health problems⁸ which current care fails to address.

Figure 8.1 Deliveries in England 2005–14



Source National Institute for Health and Care Excellence (2014)

Figure 8.2 Mode of birth in England 2005–14



Source MacArthur C, Winter HR, Bick DE et al. *The Lancet* (2002)

For many women recovery after pregnancy is seemingly uncomplicated, yet incontinence, perineal pain, anxiety and depression are common and can persist for months or years.^{8,9} Maternal mental health problems, if untreated, may have consequences for infant development^{10,11} and there is poor provision of specialist perinatal mental health services.¹² During 2009–13, 90% of UK maternal deaths occurred post birth,¹³ with late deaths (after 6 weeks and up to one year after end of pregnancy) more likely to include psychiatric causes, emphasising the importance of early postnatal identification and management (Table 8.1). These data and evidence that severe maternal morbidity (a potentially life-threatening condition or complication) is increasing^{14,15} highlight the importance of maintaining a high index of suspicion for symptoms and signs of deteriorating health post pregnancy.⁴

Table 8.1 Timing of deaths of women in the UK in relation to pregnancy 2009–13

Time period of deaths in the pregnancy care pathway	Total (n=973) Frequency (%)
Antenatal period	98 (10)
Postnatal day of delivery	84 (9)
Postnatal 1–41 days after delivery	246 (25)
Postnatal 42–182 days after delivery	246 (25)
Postnatal 183–364 days after delivery	299 (31)

Source: Knight M on behalf of MBRRACE-UK (personal communication).

3. Routine care currently offered after pregnancy

All women are offered routine postnatal contacts with healthcare professionals based in secondary and primary settings as part of universal NHS care. Services are fragmented^{16, 17} with poor data linkage across sectors and little evidence of whether care planning on transfer between health professionals occurs, despite policy recommendations.^{1, 18, 19} Midwives have a statutory duty to attend all women²⁰ and provide most early postnatal care, with obstetric input reserved for medically complicated pregnancies. Maternity support workers are increasingly used to undertake aspects of routine postnatal care, with little evaluation of their role or training needs.

Women are usually discharged from hospital within 48 hours of birth and from midwifery care at 10–14 days, when care is transferred to health visitors. A GP appointment, offered at around 6 weeks, traditionally marks the end of maternity care but few studies have addressed the effectiveness of this appointment.^{2, 21} Sampled data from the Clinical Practice Research Datalink indicates that in 179,588 deliveries between 2008 and 2014, 73.5% (131,924) had a post-natal examination documented with their GP. The remainder may not have been recorded in the electronic healthcare record, had their examination in secondary care or another clinical setting, de-registered prior to the examination or not had did not have the examination undertaken. In over 80% (109,245) of deliveries with a postnatal examination recorded, this was documented up to 8 weeks following discharge.

Revisions to the GP contract in 2004 removed an item of service payment for maternity care which, together with the introduction of direct access to midwives when women are first pregnant, has led to a decline in GP involvement.¹⁶ This raises issues about GPs' skills and competencies in providing effective care given their pivotal role in managing the long-term consequences of health risks identified in pregnancy and postpartum. Of note is that the current NHS England Standard General Medical Services Contract defines the duration of GP contact as only the first 14 days post pregnancy.²² Women who have a stillbirth or neonatal death are cared for within the same outdated model of care, despite specific recommendations that they should have contacts with a bereavement midwife/health visitor.²³ A postnatal GP check should also be offered, although a recent survey of such cases found that many women were not offered this.²⁴ Care following pregnancy termination or miscarriage should also be planned based on individual circumstances.²⁵

4. Women's views of care

Fragmentation, poor planning and communication between healthcare teams are reflected in women's views of postnatal care.^{16, 26, 27} Of 1,260 first-time mothers in one survey of postnatal care, one in eight were highly critical of their care.²⁷ An online survey of 4,000 self-selected women found that a third reported that their 6-week routine GP appointment did not meet their emotional needs and almost half said that it was not thorough enough.²⁸ Midwives appearing 'too rushed', cancelling home visits or offering insufficient advice on emotional recovery, infant feeding and birth recovery have also been reported.¹⁷

Case study – Bryony's story

Bryony chose to have her delivery at the midwife-led unit in her nearest town. However, a complication during labour meant that she had to be taken to the nearest hospital, 25 miles away, by emergency ambulance.

At the hospital, Bryony gave birth without any major problems, although she required stitches due to tearing. For the first night, Bryony stayed on the hospital's postnatal ward, which she describes as hot, noisy and crowded. She recalls how she felt unsupported with breastfeeding her baby, confused about what medication she was supposed to be taking, and unsure as to when and where she was meant to have meals. The next day, Bryony was transferred back to the midwife-led unit for one more night, where she says she felt much more supported.

Bryony then went home. For the next two weeks, she had regular midwife appointments. However, due to low resources, the midwives were unable to visit her. Instead, she had to make the trips to the midwife-led unit herself. Though her partner drove, Bryony recalls the ride being uncomfortable, particularly with her stitches.

Bryony describes the midwives' attentiveness to her baby as excellent. However, she believes that she would have benefited from more attention, and explains how the midwives asked little about her physical and psychological wellbeing. She also thinks that the midwives discharged her from their care too early, taking only her baby's wellbeing into account.

5. Revisions to routine postnatal care

There is evidence that alternative models of post-pregnancy care could benefit the general population of women giving birth. However this does not provide evidence of what model of care would improve outcomes for women with known medical, mental health and social needs. A large randomised controlled trial in the West Midlands compared standard postnatal care with a re-designed model of extended midwifery-led community care focused on maternal need and identification and management of common morbidity.² Midwives delivering the revised model undertook a final contact at 10–12 weeks which replaced the GP 6-week check. Findings showed that women who received re-designed care were less likely than women who had usual care to report mental health problems or use non-routine GP services for themselves or their infants during the first year post birth, a clinically and cost-effective difference.² A trial which assessed maternal psychological health and other outcomes following training of health visitors to systematically identify symptoms of depression and deliver psychologically informed sessions for women at risk of depression compared with usual contacts, was also effective in reducing the proportion of at risk women with a high Edinburgh Postnatal Depression Score (≥ 12) at 6 months postnatal.²⁹ The findings of these trials have not been translated into routine practice.

Opportunities to identify common and more severe maternal morbidity and promote positive lifestyle interventions continue to be missed, with clear need to revise postnatal care. Service revision could include, for example, postnatal 'triage' on transfer from secondary to primary care to determine appropriate pathways based on individual women's needs. Low risk women could receive core care from their midwife and health visitor, including a flexible final contact; for women with additional needs, earlier contacts with their health visitor and/or GP could be planned and women with most complex medical or social needs could benefit from multi-disciplinary team (MDT) review with longer-term follow-up needs discussed with their GP. There is no research evidence to guide any of these suggested changes and obtaining robust evidence prior to a radical re-think of the care pathway is essential.

The following examples of common and severe morbidity illustrate why revisions to routine post-pregnancy care are a priority if women's health needs are to be met. The role of primary care services, including the GP, is crucial for the management of pre-existing medical conditions, such as hypertensive disorders, diabetes and mental health problems, as well as management of similar pregnancy onset conditions. Evidence of how best to provide this level of support is lacking.

6. Common maternal morbidities

6.1 Incontinence

About a third of women experience urinary incontinence after pregnancy and between two-thirds and three-quarters of these women still report it 12 years later.³⁰ Faecal incontinence of varying severity occurs in up to 10% of women after birth, and over a third of women with this still report it 12 years later.³⁰ Most women with incontinence after birth report not seeking treatment, highlighting why postnatal women need to be specifically asked about health symptoms so they can be managed appropriately.

6.2 Perineal pain

Perineal laceration is the most common complication of birth.³ The National Institute for Health and Care Excellence (NICE) recommends that women are asked about perineal healing at each contact, that they should be advised about wound care to reduce potential infection, and that the perineum should be observed to monitor healing and prompt early identification of infection or wound dehiscence.¹ Women with third- or fourth-degree tears should be offered obstetrician follow-up.³¹

6.3 Mental health problems

Depression is experienced by around 13% of postnatal women.³² Other mental health symptoms such as anxiety, bi-polar disorder, eating disorders and obsessive compulsive disorders may be co-morbid with depression.^{33, 34} Women should be asked at each postnatal contact about their emotional health and encouraged to discuss how they are feeling without fear of stigma.³⁴ Approaches to management are described in Chapter 7 of this report, 'Perinatal mental health'.

7. Severe maternal morbidities

7.1 Hypertensive disorders

A multicentre retrospective analysis of 3,988 women with pre-eclampsia showed that 229 (5.7%) were diagnosed during the postpartum period and 151 women were readmitted, the average time from birth to readmission ranging from 1 to 24 days.³⁵ Eclampsia can also present after delivery with reported proportions of postpartum cases of 32%³⁶ and 36%.³⁷ Recurrence of subsequent pregnancy hypertensive disorders and effects on lifetime risk of cardiovascular disease and hypertension should be discussed with women.³⁸ An individual patient data meta-analysis found that recurrence of hypertensive pregnancy disorder in a subsequent pregnancy was 20.7%.³⁹ Pre-eclampsia was identified as a risk factor for later hypertension in a cohort of women followed for a mean of 14.1 years (OR 3.70 [2.70 to 5.05]).⁴⁰ A retrospective cohort study of 129,290 births in Scotland between 1981 and 1985 found that women with pre-eclampsia had an increased risk of subsequent ischaemic heart disease (OR 2.0 [1.5–2.5]).⁴¹ There is a dearth of evidence-based guidance on appropriate follow-up of women at increased risk post pregnancy of poorer health during their life course. A key example of this is the exclusion of pregnancy hypertension from the QRisk2 tool.⁴²

7.2 Diabetes

NICE (2015) recommends that women with gestational diabetes (GDM) whose blood glucose levels return to normal after pregnancy are offered weight control, diet and exercise advice, and have fasting plasma glucose measured at 6–13 weeks postnatally to exclude diabetes.⁴³ If not performed by 13 weeks, a fasting plasma glucose or HbA1c test should be offered, with an annual HbA1c test for women diagnosed with GDM who have a negative postnatal test for diabetes. Women diagnosed with GDM had a 7-fold increase in type 2 diabetes in one meta-analysis.⁴⁴ Again, there is a paucity of research into strategies to address this. The effects on glycaemic control for women with insulin-treated pre-existing diabetes who breastfeed should be discussed.⁴³

7.3 Cardiac disease

Cardiac disease affects 0.2%–4% of women during pregnancy⁴⁵ and was the largest single cause of maternal death in the most recent confidential enquiry.⁴ Evidence to inform postnatal management and follow-up of women with a pregnancy complicated by cardiac disease is lacking.⁴⁶

7.4 Epilepsy

During 2009–12, 14 maternal deaths in the UK were attributed to epilepsy or seizures; 12 of these women died from sudden unexpected death in epilepsy (SUDEP).⁴⁷ Women with epilepsy may have more maternity-related seizures due to altered medication compliance, poor sleep and changes in the bio-availability of their medication. Women require advice on reducing risk from seizures by

not bathing or sleeping alone⁴⁷ and should never be placed in a single room on the inpatient ward. They are similarly vulnerable postnatally and require appropriate advice about medication. Contact with multi-disciplinary epilepsy services (which do not yet exist in all regions) via an epilepsy nurse or midwifery specialist must be maintained after delivery, but there is no evidence about how best to deliver this alongside their other postnatal care needs.

7.5 Sepsis

There is limited research on incidence of postnatal wound or genital tract infection, despite concerns about sepsis-related mortality.⁴ In a prospective case control study in UK obstetric-led units (June 2011 to May 2012), 31% of postnatal women (114/365) with severe maternal sepsis were readmitted,⁴⁸ highlighting the need to raise awareness of this. Clinicians must 'think sepsis' in women who are unwell, taking urgent action if sepsis is suspected.⁴ When considering appropriate practitioner(s) to deliver new models of postnatal care, the importance of identifying sepsis and other rare but serious postnatal complications are key.

7.6 Severe mental health problems

Affective psychosis and severe depressive illness are major causes of indirect maternal death and chronic morbidity.⁴⁹ Untreated maternal depression impacts on child development, with a high risk of recurrence of depression in subsequent pregnancies.³⁴ Women with risk factors for severe postnatal mental health problems require pregnancy and postnatal care planning, with care co-ordinated across health sectors, including 'chasing' if a planned contact is missed. For severe mental health problems referral, preferably to specialist perinatal mental health services is needed, ensuring GP follow-up on discharge from the perinatal team.³⁴ (See Chapter 7 of this report, 'Perinatal mental health'.)

8. Monitoring complex medical conditions

Complex medical conditions in pregnancy impact on postnatal health, subsequent pregnancies and longer-term health.² Although evidence of effective interventions is required, GPs should ensure that recommendations for follow-up are implemented, supported by relevant information when women are discharged from secondary care. Future health risks should be discussed and pre-pregnancy counselling and positive lifestyle interventions emphasised.^{1, 38, 50}

Case study – Emma’s story

Emma has epilepsy. When she fell pregnant at 29 years old, she was assigned a high-risk team of specialist midwives, a specialist nurse and a consultant to conduct her antenatal and postnatal care. Emma faced no major complications throughout pregnancy and birth, although she had a planned Caesarean section because her baby was breech.

Emma’s biggest difficulties arose with breastfeeding. Within a few weeks of leaving hospital, she was suffering with engorged breasts and her baby was uncomfortable feeding, often pulling away while choking.

As the midwives only came to visit her once a week, Emma sought help from local ‘milk spots’, a community service where a midwife and experienced mother offer support with feeding. Since the service ran three times a week, Emma found support quickly. She says that she would have found it very hard to continue breastfeeding if she had not received help quickly. She also adds that she did not feel prepared for how painful and emotionally tiring breastfeeding would be.

Emma says that the best thing about the care she received was its continuity. She describes the comfort she felt in having the same team support her throughout her antenatal and postnatal care. Emma adds that all of her friends have had different experiences in this respect, with many finding their care significantly more fragmented.

9. Breastfeeding

The benefits of breastfeeding are well documented.^{51, 52, 53, 54} Despite increases in initiation in England (83% in 2010 from 78% in 2005⁵⁵), only 1% of women were exclusively breastfeeding at 6 months postnatally.⁵⁵ This is the minimum period recommended by the World Health Organization⁵⁶ based on a systematic review which showed protection against infant gastroenteritis, delayed resumption of menses and lower maternal postpartum weight retention.⁵⁷ Studies have consistently found that breastfeeding protects infants against gastroenteritis, SIDs and respiratory disease, as well as protecting women against breast cancer.^{52, 58, 59} Poorer cognitive development and behavioural problems have been reported among children who were never breastfed compared with those who were.⁶⁰ In England, younger women of white British ethnicity with fewer educational qualifications and living in more economically deprived settings are less likely to start or continue breastfeeding.⁵⁵ In 2010, only 58% of women under 20 years of age commenced breastfeeding compared with 87% of women aged 30 and over.⁵⁵ Robust evidence of how to increase and sustain breastfeeding, especially in disadvantaged women, is lacking, as well as research into how transition of care from midwives to health visitors could be enhanced to support women who breastfeed.

10. Contraception

Unplanned pregnancies are common and a key public health indicator, associated with poorer outcomes for women and their children compared with outcomes of planned pregnancies.⁶¹ NICE recommends that resumption of contraception is discussed with women in the first postnatal week, with protection advised from day 21 as ovulation may occur as early as day 28.¹ Changes to commissioning have occurred as a consequence of the Health and Social Care Act 2012. The All-Party Parliamentary Group on Sexual and Reproductive Health reviewed the commissioning of sexual and reproductive health services in 2012. It recommended that the Department of Health set out how contraceptive services be commissioned and that Public Health England assess the indicators used in the Public Health Outcomes Framework to monitor sexual and reproductive health.⁶²

Responsibility for procurement of services, including those providing long-acting reversible contraception (LARC), is now with local authorities; this could limit access to services previously available to women from their local general practice. LARC methods are more clinically and cost-effective than the combined oral contraceptive pill but are less commonly used.⁶³ Increasing access to LARC post pregnancy would provide better choice for women with respect to planning and spacing a future pregnancy, and could be discussed prior to delivery and fitted at birth (see Box 8.1).

11. Conclusion

Postnatal contacts offer opportunities to identify and implement effective care to reduce maternal morbidity and promote longer-term physical and mental health, including improved outcomes of subsequent pregnancies and family health. Current service provision and content is not utilising these opportunities.

There is a paucity of robust evidence underpinning the current organisation and provision of postnatal care: research is urgently needed into the appropriate interventions to include in a comprehensive package of care, assessing and addressing the individual needs of all women. In addition to the evidence gaps, the following elements could be investigated in a commissioned programme of research or a themed call through the National Institute for Health Research, reflecting the Medical Research Council Complex Interventions framework. Areas for priority research themes include:

- optimal models of MDT management for women with medically and/or socially complex pregnancy to promote integrated care
- the role of triage of women on transfer from place of birth
- variation in the timing and routes of access to postnatal contacts
- the benefit of the 6–8 week postnatal check and timing of discharge from maternity care
- evaluation of the role of maternity support workers.

12. Authors' suggestions for policy

- To offer women and infants the 'best start', policymakers need to prioritise interventions to improve services for women after birth alongside priority accorded to antenatal and intrapartum care. Greater investment in the postnatal maternity care workforce in primary, secondary and tertiary services, including mental health services, is urgently required
- All healthcare professionals need appropriate skills and competencies to identify common and severe physical and psychological maternal morbidity and to know how to take action. The changing health profile of women giving birth has consequences for clinical training. Clinical training must adapt appropriately. This is a particular issue in primary care. A good example of teaching resources already available includes work developed by healthtalk.org based on the experiences of women who had severe medical complications in pregnancy (www.healthtalk.org/peoples-experiences/pregnancy-children/conditions-threaten-womens-lives-childbirth-pregnancy/topics).
- Restrictions on access to contraceptive services could be detrimental to women's physical and psychological health and should be removed.
- Clinical commissioners and service providers should monitor and report postnatal readmission rates for women and infants.
- Data to inform postnatal outcomes for maternal and infant health are inadequate. The establishment of a robust maternity dataset which includes data on postnatal systems, processes and outcomes and which links across secondary and primary care providers is needed.
- The current national maternity review presents an opportunity to consider how postnatal care could make a demonstrable difference to outcomes for women, their babies and families.

Box 8.1 Department of Health Missed Opportunity Programme: cost-effectiveness

Element a) Increase access to LARC methods across the population

Increased access to contraception, particularly LARC methods, for women of all ages, particularly focused on those areas where current provision is patchy due to lack of provision in primary care and limited access in more specialist services.

Element b) LARC post birth within maternity services

Encouraging and enabling women to use a LARC immediately after giving birth, to support women plan and space subsequent pregnancies.

Element c) LARC consultations before a woman's abortion

Encouraging and enabling women to use a LARC immediately after an abortion, there is evidence that this can reduce repeat abortion.

Costs for all three options would be needed for training staff (including doctors, nurses and midwives) to fit and counsel women on use of these methods and additional funding for the method itself which has higher upfront costs. There will also be the cost of developing a basic on line training package for non-specialists to raise the profile of the benefits of effective contraception.

Savings for all three options would follow from a reduction in unplanned pregnancies. When women switch from the oral contraceptive pill to LARC there is an improvement in the failure rates for typical usage, thus there would be fewer unplanned pregnancies. These savings will be captured as direct NHS savings through fewer abortions, miscarriages and births and there are also benefits to the wider public purse.

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Chapter 9

Psychosocial factors and the menopause: the impact of the menopause on personal and working life

Chapter lead

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Psychosocial factors and the menopause

PERSONAL AND WORKING LIVES

HOW WOMEN CAN HELP THEMSELVES TO HAVE A BETTER EXPERIENCE OF THE MENOPAUSE



STOP SMOKING, TAKE MODERATE EXERCISE AND EAT HEALTHY DIET



PARTICIPATE IN PSYCHOEDUCATIONAL AND HEALTH PROMOTION PROGRAMMES ABOUT THE MENOPAUSE



TALK TO CO-WORKERS AND LINE MANAGERS IF THEY HAVE TROUBLESOME SYMPTOMS AT WORK

HOW HEALTHCARE WORKERS CAN SUPPORT WOMEN BEFORE AND DURING THE MENOPAUSE



CONSIDER THE MENOPAUSE IN ITS BIOPSYCHOSOCIAL CONTEXT



PROVIDE EARLY INFORMATION ABOUT THE MENOPAUSE, HEALTH AND AGEING



PROMOTE HEALTHY BEHAVIOURS: SMOKING CESSATION, PHYSICAL ACTIVITY AND HEALTHY DIET



ENCOURAGE WOMEN TO TALK OPENLY TO PARTNERS, FAMILY, FRIENDS AND EMPLOYERS AND EDUCATE THEM IN HOW TO BE SUPPORTIVE



CONSIDER CBT FOR HOT FLUSHES, NIGHT SWEATS AND SLEEP DISRUPTION

HOW EMPLOYERS CAN SUPPORT WOMEN BEFORE AND DURING THE MENOPAUSE



FLEXIBILITY OF WORKING HOURS AND ARRANGEMENTS



ENCOURAGE WOMEN TO TALK TO CO-WORKERS AND LINE MANAGERS IF THEY HAVE TROUBLESOME SYMPTOMS AT WORK



AWARENESS OF MANAGERS ABOUT THE MENOPAUSE AS A POSSIBLE OCCUPATIONAL HEALTH ISSUE



CHALLENGE NEGATIVE EXPECTATIONS ABOUT THE MENOPAUSE AND STEREOTYPICAL ATTITUDES TOWARDS MID-AGED AND OLDER WOMEN



ACCESS TO INFORMAL AND FORMAL SOURCES OF INFORMATION ABOUT THE MENOPAUSE FOR EMPLOYEES



IMPROVEMENTS IN WORKPLACE TEMPERATURE AND VENTILATION

1. Key statistics

- The menopause is defined as the last menstrual period that occurs: on average this happens in British women at the age of 51 years.
- There are over 3.5 million women aged between the ages of 50 and 65, in employment, in the UK.
- Most women do not report the impact of menopausal symptoms as bothersome, but three-quarters of women do still seek advice about how to manage their menopausal symptoms.
- An estimated 20–25% of women find that vasomotor symptoms and related symptoms such as sleep disruption, fatigue and difficulty concentrating adversely affect the quality of both their personal and working lives.

Definitions

In this chapter:

- **'menopause'** refers to the last menstrual period that occurs
- **'menopause transition'** refers to regular menstruation, but with:
 - a) change in cycle length, or
 - b) two or more missed periods, and
 - c) at least one intermenstrual interval \geq 60 days
- **'post-menopause'** refers to 12 months after the final menstrual period.

Informed by: Harlow SD, Gass M, Hall JE, Lobo R et al. Executive summary of the stages of Reproductive Ageing Workshop +10. *Menopause* 2012; 19 (4): 105–15.

2. Introduction

In Britain, nearly three-quarters of women seek advice about menopausal symptoms, although for most the impact of those symptoms is not self-reported as bothersome.¹ For an estimated 20–25% of women, however, vasomotor symptoms (VMS) (or hot flushes and night sweats) and related symptoms such as sleep disruption, fatigue and difficulty concentrating adversely affect the quality of both their personal and working lives.^{2, 3, 4, 5, 6, 7} Multiple, often interacting, factors – physical, psychological, work related and social – may determine the experience of the menopause for women and affect whether or not they decide to seek advice or treatment.⁴

The diagnosis and clinical management of the menopause are addressed elsewhere and will be further covered by National Institute for Health and Care Excellence (NICE) guidance due to be published in November 2015. This chapter considers psychosocial factors relevant to the experience of the menopause and suggests strategies to improve women's quality of life during this time. Psychosocial factors may determine what sort of advice and treatment, if any, women seek. An understanding of these factors opens up avenues for non-clinical approaches, such as cognitive behavioural therapy (CBT), to reduce troublesome symptoms. This may be helpful for women for whom hormonal treatment is contraindicated, or for those who prefer not to use such treatments.

Although hormonal treatment is considered an effective treatment for women with severe vasomotor symptoms,⁸ its usage has varied over recent decades as a consequence of uncertainty about risks and benefits. In a study of 10,000 women, 90% of those who discontinued hormonal treatment reported a return of VMS and sought alternative strategies.^{9, 10} It is hoped that highlighting the psychosocial correlates of problematic menopause, and non-clinical strategies for improving quality of life during this time, will be useful for women, their families, healthcare practitioners and employers. Non-clinical strategies could include, for example, moderate exercise.¹¹

3. Menopause symptoms

The menopause literally means the last menstrual period that occurs; on average this happens in British women at the age of 51. However, the timing and experience of the menopause are highly variable and can be affected by, for example, surgery or disease. While many symptoms are attributed to the menopause, such as irritability, memory problems, low mood, tiredness, aching limbs, loss of energy and dry skin, these are not specific to the menopause. Vasomotor symptoms are the main early physical symptoms of the menopause; they are typically described as sudden feelings of heat in the chest, neck and face, usually accompanied by skin redness and profuse perspiration and/or palpitations, and sometimes followed by shivering while body temperature returns to normal. They vary in frequency and may last between a few seconds to an hour.⁴ They may also be instrumental in how women experience other attributed symptoms, such as sleep disturbance and fatigue. Vasomotor symptoms usually continue for between four and eight years although they may persist for ten years.^{9, 12}

4. Culture and attitudes

Cross-cultural studies demonstrate wide variations in symptom perception and reporting in women from different ethnic origins and living in different countries; for example, women in western countries tend to report more hot flushes compared with those living in India, Japan and China.¹³ Explanations of these differences include lifestyle, social factors and reproductive patterns, as well as beliefs and attitudes to ageing and the menopause, and the roles and social status of mid-life and older women.

Health professionals might underestimate the extent to which the meaning of the menopause and attitudes towards treatment are influenced by religion, ethnicity, medical practices and personal values. For example, not having menstrual periods, the lack of a need for contraception or the burden of repeated pregnancies is often met with relief.¹⁴ There are also cultural differences in women's attributions of different types of symptoms (eg visual problems and high blood pressure) to the menopause, which in turn could result in some women not seeking or receiving appropriate healthcare.¹⁵ Negative beliefs and attitudes, and expectations held before the menopause predict symptom experience during the menopause.^{16, 17} Broader cultural and social attitudes can influence the meaning of the menopause for the individual woman and impact upon her experience of it.

Negative cognitive and emotional appraisals about hot flushes (social embarrassment, disgust, feeling out of control and frustration) and behavioural reactions (such as avoiding social situations) are associated with more problematic flushes and sweats.^{18, 19, 20} In turn, these may have a negative impact on sleep quality, emotional, social and work-related functioning, and women's abilities to deal with symptoms.

5. Lifestyle

With regard to lifestyle, smoking has been associated with an earlier menopause, as well as more frequent hot flushes,⁴ and caffeine use with more frequent flushes.²¹ Physically active women tend to report higher quality of life and fewer hot flushes compared with inactive women.²² However, when exercise or physical activity has been evaluated in randomised controlled trials as an intervention, it is not effective in specifically alleviating hot flushes and night sweats, but may improve aspects of quality of life such as sleep and depression in post-menopausal women.^{11, 23}

Evidence from a prospective study of nearly 27,000 working women suggested that mid-life and older women who reported increased physical activity demonstrated a reduced subsequent risk of mental ill-health (as measured by the General Health Questionnaire) in comparison with those who did not increase physical activity. This protective effect of increased physical activity did not hold for younger women.²⁴ It may be that weight control plays a role: weight tends to increase with age and, while there is a redistribution of fat during the menopause to the abdomen, weight gain is not a necessary consequence of the menopause; there is some evidence that weight loss, by means of exercise and a healthy diet, can lead to improvements in quality of life and also to improvements in vasomotor symptoms.²⁵

6. Impact on personal life

Mid-life is typically a life stage when women are dealing with demanding life events and responsibilities, such as work, health problems, caring for elderly relatives, bereavement, dealing with adolescent children, and resulting changes in personal roles and social relationships. Within this context menopausal symptoms can cause discomfort, social embarrassment and disruption of sleeping patterns, which impact on quality of life.²⁶ Various factors predict the extent to which vasomotor symptoms are problematic or troublesome; for example, their chronicity, past surgical menopause (oophorectomy or hysterectomy), higher body mass index, lower physical activity levels, smoking and ethnicity.^{4, 27}

Although there is wide variation among women, libido and sexual functioning can be affected by ageing, the menopause and other factors, such as depression, anxiety, stress, relationship problems, negative beliefs about ageing and sexuality, partners' sexual functioning, poor body image and certain medications.^{27, 28} Vaginal dryness, associated with lower levels of oestrogen, can significantly increase the likelihood of painful intercourse (dyspareunia), which in turn can reduce sexual responsiveness and the desire for sex.²⁹ Not surprisingly, good communication and emotional support within a relationship have been found to be helpful.³⁰

Women experiencing troublesome menopausal symptoms report significantly lower levels of health-related quality of life and greater use of healthcare services than women without symptoms.⁶ Evidence also suggests that it is the rating of how intense or problematic vasomotor symptoms are, rather than their frequency, that is associated with a reduction in health-related quality of life.³¹

7. Mental health

In addition, a range of psychological and social factors are associated with more troublesome vasomotor symptoms, such as current stress, anxiety and depression during and prior to the menopause, certain beliefs about the menopause and its symptoms, low socio-economic status and low levels of education.^{17, 18, 31}

In general, depression is more prevalent during mid-age for adult men and women, although women have a greater risk of depression than men.³² Evidence from the *Household Survey for England* suggests that this mid-life increase in depression is more common among lower income groups for both men and women, thus emphasising the role of social influences.³³ Past depression is the main predictor of depressive symptoms during the menopause.³⁴ Depressed mood should not be attributed automatically to a hormonal cause or to the menopause. Mishra and Kuh (2012) looked at changes in psychological symptoms (including depression) across the stages of the menopause for women in the *1946 British Birth Cohort Study*; they found that 10% of women may be at a higher risk of such symptoms during the transition to the menopause, but that this risk tends to decrease post menopause, ie for most it is relatively transient.¹ Factors associated with psychological symptoms and depressed mood for mid-life women include past history of psychological problems, social factors (educational and occupational status), poor health, surgical menopause, stressful life events, cigarette smoking, chronic or severe vasomotor symptoms, attitudes to the menopause and ageing, and early life circumstances and experiences.^{1, 35, 36}

An early menopause can be distressing due to its impact on fertility and concerns about health.²⁹ There are also complex interactions between depression and menopause-specific changes, for example two-way interactions between troublesome hot flushes and depression or stress. Although hormonal changes during menopause might partly account for the increased risk of depression, overall it is important to consider the psychosocial context of women's lives, and the interactions between such factors and menopause-specific changes; in other words, a biopsychosocial approach is recommended.³⁷

8. Working lives

There are over 3.5 million women in employment aged between 50 and 65 in the UK, many of whom are in senior roles and at the peak of their careers.^{38, 39} In a recent UK study of nearly 900 working women, the main symptoms which women attributed to their menopause that caused them difficulties at work were poor concentration, tiredness, poor memory, feeling low/depressed and lowered confidence.⁵ Of these, lowered confidence, poor concentration and poor memory were particularly troublesome for them at work in comparison with their non-working lives.

Women have encountered criticism and ridicule about menopausal symptoms from co-workers and managers.^{40, 41} It is important not to underestimate the accumulated and negative consequences for mental health of these often unintentional slights that are experienced by marginalised groups.^{42, 43} They are difficult to dismiss and to confront. Women are generally reluctant to divulge their menopausal status or symptoms, but particularly so at work, where fear of stigmatisation is common, and where poise and control are highly valued.⁴⁴ This is especially the case where their manager is male, or is younger than them, whether male or female.^{5, 44}

Some women feel that their menopausal status opens them up to being stereotyped and prefer not to reveal age- and gender-related matters at work. When women take sickness absence because of menopausal symptoms, they do not always divulge the real reason to their manager. However, when women do disclose difficulties to co-workers and line managers, their subsequent support is highly valued.⁵

8.1 Performance at work

Working women have reported that menopause symptoms, such as tiredness and difficulty concentrating, impact negatively on their work performance^{4, 45} and some report that they work harder to compensate for these difficulties so that performance is not negatively affected.⁵ Prospective studies of cognitive performance during menopause transition are scant, but any impact on cognition is likely to be subtle and transient.⁴⁶

Some evidence suggests that menopause symptoms may have a detrimental effect on work capacity for some women, particularly if depressive symptoms are also reported,^{6, 7, 47, 48, 49} but more research is needed to clarify whether women's actual performance is affected.³⁹ A study that sought line managers' views of women's performance concluded that most continued to do their job well during these years.⁵⁰

8.2 Menopausal symptoms at work

At work, hot flushes are reported as a source of distress and embarrassment for some women, leaving them feeling at odds with their desired professional image. Concerns about the reactions of others and fear of social stigma are common at work and in social situations.⁵⁴ Certain situations at work are reported to precipitate or exacerbate vasomotor symptoms: for example, formal meetings, high visibility work such as presentations, and working in hot and poorly ventilated environments.⁵ Many women work in environments where it is not possible to open windows for fresh air, or where doing so in shared offices or workspaces risks creating interpersonal difficulties.

Working women have reported that seeking to reduce the impact of troublesome menopausal symptoms on their working lives was the main (or one of the main) reasons why they decided to try hormone treatment.⁵ The majority of these reported that hormone treatment enabled them to cope better with work.

9. Conclusion

Given the influence of both physiological and psychosocial factors on the experience of the menopause, we would argue that public health strategies might usefully target the broader psychosocial factors that impact upon women's quality of life during the menopause transition and post menopause. The challenge is to develop approaches that can engage with a variety of experiences, values and lifestyles that normalise the menopause, but at the same time provide information and strategies for those women who have troublesome symptoms.

9.1 Improving education and awareness

There is evidence that women who participate in psychoeducational and health promotion programmes have more accurate knowledge, more positive attitudes regarding menopause, less discomfort associated with changes at these stages, and more frequent engagement in healthy habits than women who do not participate in these programmes.⁵⁵ Women may simply want information and discussion about what might be expected as well as the options that are available to them; not all choose medical treatment. NICE guidance on diagnosis and management of the menopause (due to be published in November 2015) should offer an up-to-date synthesis of the evidence on clinical assessment and management. Further resources include 'A Practitioner's Toolkit for Managing the Menopause'⁵⁶ which offers algorithms for the reasons why a woman might present, determination of menopausal status, issues that might influence treatment decision-making, hormonal and non-hormonal treatment options, and advice on symptom management and patient review. Healthtalk.org is an online resource for women and healthcare practitioners where information about women's experiences of the menopause can be accessed.⁵⁷

9.2 Health promotion around the menopause

The menopause is a time when women frequently seek advice from their doctors. It is also arguably an important opportunity to encourage positive health-related behaviours such as stress reduction, smoking cessation, dietary intake and increasing physical activity. Such changes might benefit women going through the menopause transition as well as offer prevention of longer-term health problems. Targeting women at 40 or 45 in preparation for the menopause has been advocated.^{58, 59}

9.3 Treatment options

On an individual level, while hormone treatment is clearly helpful for some women in dealing with severe symptoms,³² many are reluctant to use it. Provision of balanced information about the risks and benefits of hormone treatment and alternatives is important. Psychological interventions, such as CBT, can be offered to reduce anxiety or improve mood.³² CBT has also been developed specifically for hot flushes and night sweats, including psychoeducation

and evidence-based CBT for hot flushes, stress, night sweats and sleep. This approach has been shown to reduce significantly the impact of hot flushes and night sweats in randomised controlled trials with breast cancer patients^{59, 60} and with well women.⁶¹ It can also improve mood and quality of life. Self-help CBT, with minimal guidance from health professionals, has been found to be as effective as group CBT for these symptoms.⁶² It appears to work by changing cognitive appraisals (women's perceptions, attitudes and beliefs about the menopause and symptoms) as well as using helpful behavioural strategies, such as using calm breathing. Accepting symptoms and not reacting with frustration, or anxiety, are associated with less problematic flushes and sweats.^{19, 20} Thus, CBT can be a safe and effective self-management strategy, or an alternative approach to medical treatments.^{63, 64}

An example of how CBT helped one woman is given in the case study "Sarah's story".

9.4 Improving working lives

With regard to working life, women have reported a wide range of individual coping strategies to be helpful during the menopause. These include psychological (distraction, making light of matters); social (talking with other women who have gone through the menopause); informational (increasing knowledge about the menopause); practical (double checking work, making lists); organisational (changing working hours, adopting a more flexible approach to tasks); and changing health behaviours related to exercise, sleep and diet.⁵

Possible benefit may lie in exploring women's attributions of co-workers' and line managers' perceptions to the menopause in general, and to hot flushes in particular. A study with 290 working men and women (aged 25–45) enquired as to their attributions and reactions to a hypothetical scenario of a female work colleague displaying hot flush symptoms. The majority did not attribute redness or profuse sweating to the menopause, but to various other causes such as stress, a cold, or a hot room. Perhaps not surprisingly, women were more likely to attribute such symptoms to the menopause than men were. Importantly, however, reactions were generally neutral, empathic or positive.⁵⁴ These findings suggest that women's beliefs about others' reactions may be unduly negative; this evidence is used to reassure women in CBT for hot flushes.^{63, 64}

9.5 Advice available for employers

The British Occupational Health Research Foundation has published evidence-based advice for employers about the menopause and work.⁶⁵ Based upon what women say would be helpful, they advocate:

- greater awareness of managers about the menopause as a possible occupational health issue
- flexibility of working hours and working arrangements
- better access to informal and formal sources of support
- improvements in workplace temperature and ventilation.

The Trades Union Congress has produced similar advice for union representatives.⁶⁶ However, managers cannot provide support or offer suitable adjustments if they are not made aware of problems. It is important for employers to foster a culture where it is acceptable to discuss menopause symptoms (and any other health problem) that may impact on working life. Employers could provide training for managers on the menopause and other health issues relevant to the management of an age-diverse workforce. Providing information about coping with the menopause at work and facilitating the establishment of a support network, much of which could be online,⁶⁷ conveys a reassuring message. Larger employers could call upon the services of occupational health functions.

An example of how expert advice at work helped one woman is given in the case study "Fiona's story".

Case study — Sarah's story

Sarah was having an average of eight severe hot flushes during the day, as well as night sweats. Her sleep was adversely affected to the extent that she often felt too tired to engage in social activities. Relationships within the family were becoming strained. She found hot flushes embarrassing, particularly in meetings at work. She began to feel that the symptoms were taking over her life. Sarah undertook a short course of cognitive behavioural therapy for hot flushes which involved learning strategies to relax, focusing on her breathing at the onset of a hot flush, and learning how to deal with stressful situations more effectively. She also learnt how to challenge her usual negative thoughts about hot flushes and the menopause. She found these approaches helpful and reported that her flushes became milder and less frequent.

Afterwards she said: 'I would say that it's been excellent for me. I initially thought that I could do absolutely nothing to help myself with menopausal symptoms... I really thought that everyone was staring at me when I was hot and bothered. Realising that I could control things has been excellent for me... I know that I have now got the tools to deal with it. When I feel a hot flush coming on, I know not to panic about it, just to use my breathing exercises. I'm still having them but I don't let them worry me really. I just think, 'Here you come... gone in a minute,' which is a good thing.'

Case study — Fiona's story

Fiona, a 51-year-old administrative assistant, was referred to the Occupational Health Department by her manager. He had raised concerns about her behaviour and performance which he felt had deteriorated over a three-month period. She had previously been an excellent employee but had started coming to work late and was making mistakes. In addition, she had recently started covering up her mouth when talking to him. He requested an occupational health assessment to see if there were any underlying health issues that could account for these problems. He particularly wanted to know if Fiona had an undisclosed alcohol problem (possibly covering up her mouth to disguise the smell of alcohol on her breath).

Fiona saw the Occupational Health Consultant Physician (OHP) and gave the following story. She had started experiencing hot flushes around four months previously. These were now occurring several times a night, with significant sleep disruption. In addition, she had noticed an unpleasant taste in her mouth and was worried that other people might think she had bad breath, which is why she had started covering up her mouth. She had been teetotal all her life and was amazed that her manager had thought she might be drinking to excess.

The OHP explained that her symptoms were likely to be due to the menopause and that, as well as causing night sweats, changing hormone levels could affect salivary glands and lead to a dry mouth, bitter taste and bad breath. Fiona was very relieved that there was an explanation for her symptoms and in retrospect was amazed that she had not worked this out for herself. She was given an information sheet on the menopause, advice on how to cope with hot flushes and a dry mouth, and websites for further support. It was also recommended that she went to discuss her symptoms with her GP.

She was worried that her young male manager would not be knowledgeable or sympathetic about the menopause, but gave consent for the OHP to speak to him. The OHP informed the manager that Fiona was suffering from menopausal symptoms that were affecting her sleep, leading to her oversleeping in the morning and being late for work. The chronic tiredness was affecting her concentration and she admitted she had made a few mistakes. It was also explained that she had a menopausal associated problem with a dry mouth, which was why she had been covering up her mouth.

The manager was reassured that she did not have an alcohol problem and that she had been given help and support to cope better with her symptoms.

Once the manager was aware of the problem (and was relieved that serious health problems had been excluded), this allowed a dialogue to start about how to support Fiona. The OHP wondered whether flexible working might be an option if Fiona had experienced a bad night, and her manager was able to accommodate this. He was also given an information sheet on the menopause explaining how to support employees during this period of their lives.

Fiona returned for review a month later and was feeling significantly better. Although she was still experiencing hot flushes she now understood their cause and had tools to help her deal with them. Her dry mouth had improved with regular drinks and chewing sugar-free gum. The relationship with her manager had significantly improved and he had agreed to flexible working so that she could come in late if she had had a bad night and then stay working later. She was less tired and had not made any further mistakes. She had also seen her GP and had discussed the pros and cons of hormone treatment, and was aware that this was an option for the future, depending on her symptoms.

Please note – both of the case studies on this page are fictitious.

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Chapter 10

Incontinence and prolapse

Chapter lead

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Incontinence in women

Over 5 million

WOMEN IN THE UK
HAVE INCONTINENCE



50%

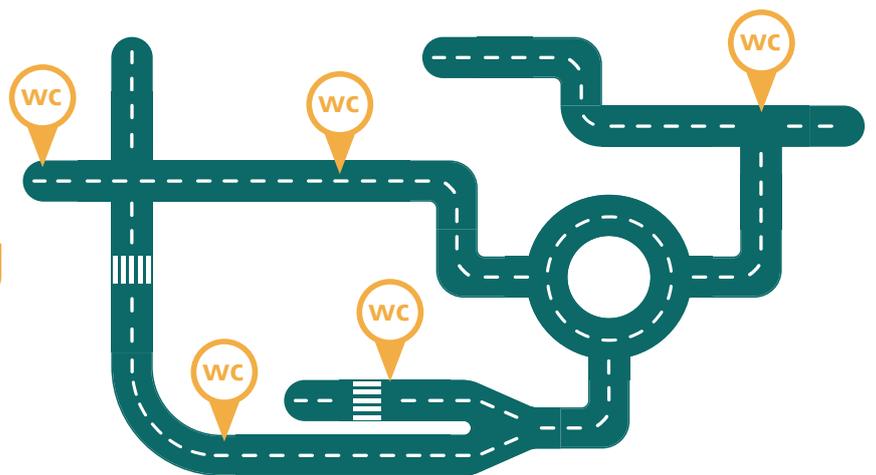
of women aged
18 to 65 years

REPORTING INCONTINENCE ARE
MODERATELY OR GREATLY
BOTHERED BY IT

23%

of women reporting
incontinence

PERFORM 'TOILET MAPPING'
AND AVOID AREAS WHERE ACCESS
TO TOILETS MAY BE LIMITED



1. Key statistics

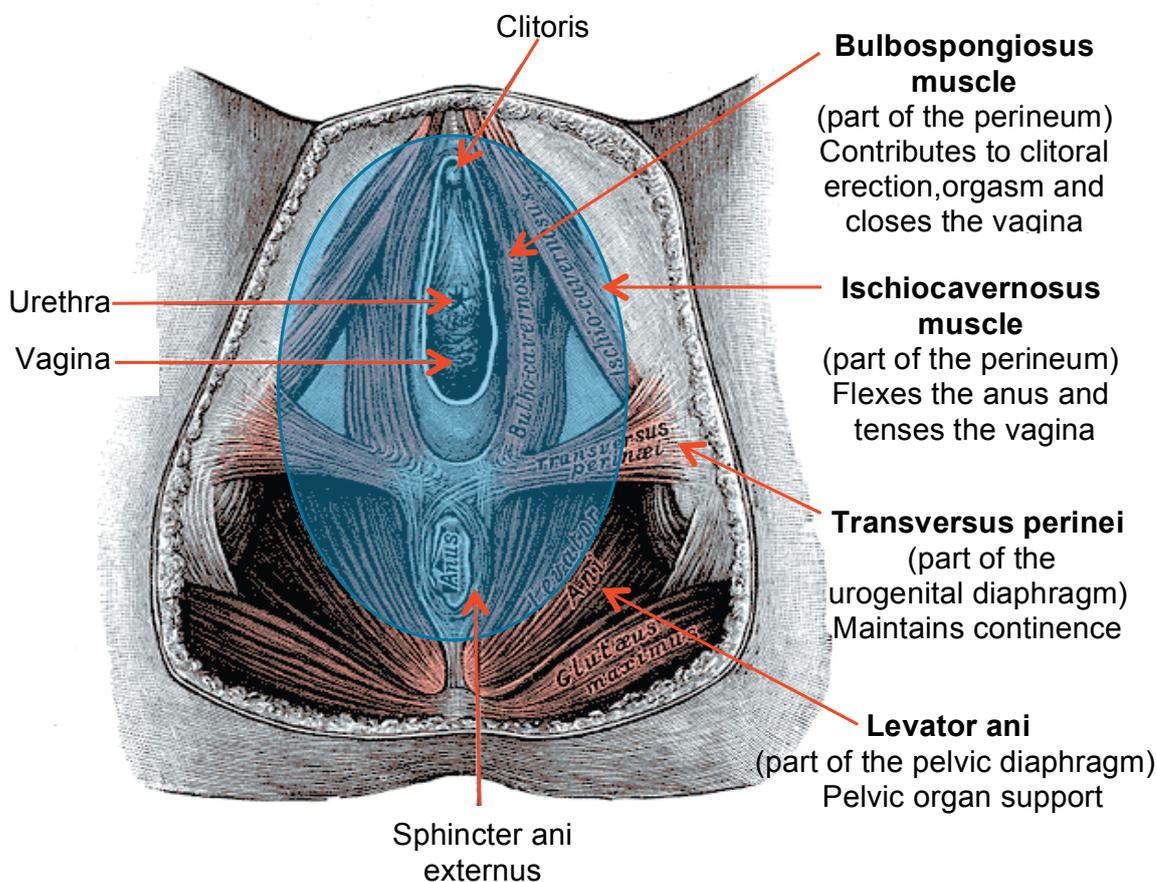
- Over 5 million women are affected by incontinence in the UK.
- 50% of women between 18 and 65 years of age reporting incontinence are moderately or greatly bothered by it.
- 27% perform 'toilet mapping' and will avoid areas where access to toilets may be limited.
- Approximately 23% state that it affects their sex life, 23% say that it reduces their activity and 25% feel embarrassed or frustrated.
- 31% dress differently because of their symptoms.
- Urinary incontinence adversely impacts on other co-morbidities and workplace absences.
- Incontinence is associated with falls and strokes in women over 80 years of age.

2. Introduction

Having children is a significant part of many women's lives. But, in a proportion of women, pregnancy and childbirth may impact adversely on the pelvic floor, leading to gross disturbances of bladder, bowel and sexual function. Incontinence and prolapse arise from dysfunction of the pelvic floor. These effects persist in a significant proportion of women in later years.^{1,2} Women with incontinence may minimise their symptoms, be unwilling to consult their doctor and feel that their problems are not taken seriously by their healthcare providers.² Failing to recognise issues early enough to institute simple therapy, such as physiotherapy, may result in significant long-term consequences, necessitating the need for multiple hospital appointments, long-term medication, expensive pad provision, surgery and, in some cases, institutionalised care.

The structures comprising the pelvic floor and the function of each muscle group can be seen in Figure 10.1. During childbirth (the head is outlined in blue in Figure 10.1), the perineal body distends and then recoils.³

Figure 10.1 The pelvic floor showing different muscle groups and their function (blue circle represents position of fetal head in childbirth)



Source Adapted from an original image in Thieme Atlas of Anatomy (General Anatomy and Musculoskeletal System) THIEME 2007

Incontinence and prolapse result from pelvic floor dysfunction, which occurs when the complex structures of the pelvic floor and the pelvic organs are damaged. As a consequence, bladder or bowel incontinence and pelvic organ prolapse may occur along with deterioration in the ability of the bladder, bowel and vagina to function normally. The latter are generically known as bladder, bowel and sexual dysfunction.

Typically, bladder dysfunction presents with stress urinary incontinence (involuntary loss of urine on exertion), urgency often with urgency urinary incontinence (involuntary loss of urine associated with urgency), or mixed urinary incontinence (a combination of both stress urinary incontinence and urge urinary incontinence) together with problems with daytime urinary frequency and/or nighttime disturbance of sleep due to urinary frequency. Bowel dysfunction can manifest as faecal urgency, faecal incontinence of liquids, solids or flatus, constipation or obstructed defecation. Sexual dysfunction can present as disturbance of pelvic floor sensation during/preceding sexual intercourse, pain, vaginal laxity and obstructed penetration. Pelvic organ prolapse presents as a pelvic pressure, 'something coming down', a bulge, a need for splinting in order to defecate or lower backache.

3. Aetiology

The aetiology of pelvic floor failure is multi-factorial. Genetic conditions which affect the collagen in the body, such as joint hypermobility syndrome, can predispose to incontinence and prolapse due to failure of the pelvic floor muscles to support the structures of the pelvis.^{4,5} Pregnancy, with its challenges of hormonal influence, increased weight and ligament laxity, plays an important role, as does a prolonged second stage of labour,^{6,7} operative vaginal delivery,⁸ larger babies and multiple births. Ageing and the menopause,⁹ obesity¹⁰ and neurological conditions may cause pelvic floor damage. Chronic conditions leading to increased intra-abdominal pressure (eg chronic constipation or chronic bronchitis),¹¹ female genital mutilation,¹² previous radical pelvic surgery¹³ and radiotherapy also play a role.¹⁴ Maintaining strength in these muscles is crucial to minimising pelvic floor failure and its consequences.¹⁵

4. Prevalence

In 1996, it was estimated that 50% of the adult female population in the UK (some 16.1 million women) were living with daily symptoms of pelvic floor dysfunction that had been present for at least six months, but a more recent study puts this figure at 40% of the population for urinary incontinence and roughly 8% for utero-vaginal prolapse.¹⁶ The exact prevalence for pelvic organ prolapse is difficult to estimate, however in one study of over 27,000 post-menopausal women over 50, 40% had some degree of prolapse. Estimates of prevalence of urinary incontinence in women vary between 25% and 45% in most studies.¹⁷

5. Incontinence

5.1 Urinary incontinence

Prevalence estimates for urinary incontinence vary widely, due to differences in populations sampled, definition and measurement of incontinence and survey methodology.^{18,19} Prevalence data from a Norwegian cohort have been used in National Institute for Health Research Health Technology Assessments and the 2013 National Collaborating Centre for Women and Child Health's 2013 Urinary Incontinence guidance.²⁰

It is estimated that 5 million women in the UK over the age of 20 suffer from urinary incontinence, which manifests as stress urinary incontinence, overactivity of the bladder (+/- urgency urinary incontinence) or voiding dysfunction with resultant overflow incontinence. The aetiological factors specific to women's life course are pregnancy, childbirth and the menopause. Oestrogen deficiency, which starts at the menopause or when breastfeeding, has a direct effect on pelvic floor and pelvic organ function by altering the collagen.²¹

In women over the age of 80, 36% are living with urinary incontinence.²² Many of them are unable to look after themselves at home because of this, particularly if cognition is affected, and are looked after in residential institutions. The greater the severity of urinary incontinence, the more negative the impact on a woman's health-related quality of life.²³

5.2 Faecal incontinence

Faecal incontinence remains a greater taboo subject than urinary incontinence; it is quite prevalent, with an estimated 1–10% of adults living with this condition.^{24,25} The incidence is higher in women, in the postnatal period,¹⁶ in older adults and nursing home residents, and there is a strong association with urinary incontinence, which often co-exists in the same patient.²⁶ Faecal incontinence is a marker for increased mortality in older adults; in a study of patients after stroke, 12-month mortality was 20% compared with 8% in continent residents²⁷ and was a marker for terminal illness in patients admitted to acute elderly care wards.²⁸

6. Pelvic organ prolapse

6.1 Aetiology

Pelvic organ prolapse may affect one or all compartments of the vagina. If this includes the anterior vaginal compartment, which includes the bladder (cystocele) and urethra (urethrocele), it is usually associated with bladder dysfunction. If prolapse affects the posterior compartment, which includes the rectum (rectocele), it is often associated with ano-rectal dysfunction. If the middle or apical compartment is involved this may include prolapse of the uterus, the vaginal vault (post-hysterectomy) or occasionally small bowel prolapse into the pouch of Douglas (enterocele) (see Figure 10.2) and will present with symptoms dependent on the structure which is prolapsing. Damage to the perineal body gives rise to deficiency and predisposes to defects not only of the rectocele, which is expected, but also the enterocele at a higher vaginal level.

6.2 Prevalence

Pelvic organ prolapse is common in women, affecting 30.8% of parous women over 50 years of age, with a lifetime prevalence risk estimated at 30–50%.²⁹ Not all prolapse is symptomatic. A recent community dwelling study of a cohort of 1,832 women, reported that symptoms of a bulge/lump into the vagina and a bulge/lump out of the vagina were present in 8.4% and 4.9%, respectively.³⁰ In a cohort of parous Scottish women, the lifetime risk for surgery for pelvic organ prolapse was 4.4% by the age of 80.³¹

7. Impact

7.1 The patient

The impact of pelvic floor dysfunction and all its ramifications on women's lives can be quite devastating. It can affect their ability to work and their personal, sexual and social relationships (examples are given in 1. Key statistics, at the start of this chapter).

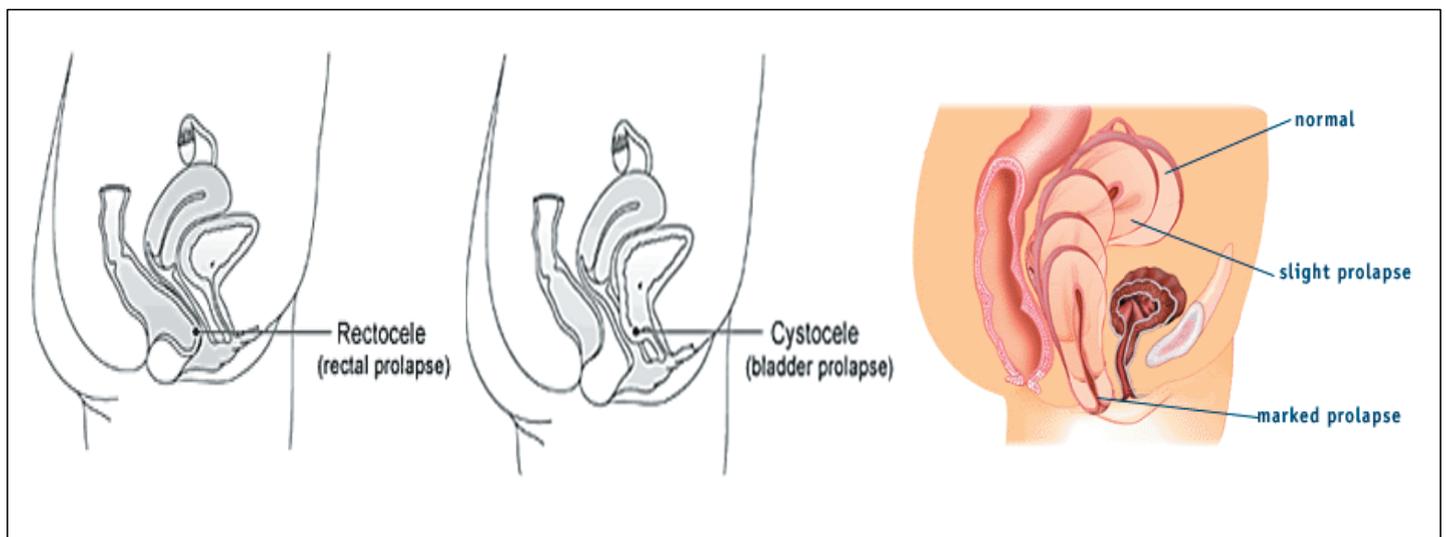
7.2 Impact on society

A retrospective study from the USA of urgency urinary incontinence (UUI) in employees versus those without UUI, between 2001 and 2011, showed that:

- employees with UUI (predominantly women) had statistically significantly higher sick leave (30%), short-term disability costs (74%), more sick days (22%) and short-term disability (99%) days than controls (all $p \leq 0.02$).³²
- employees with UUI had 47% greater total absence costs and 63% more absence days than employees without UUI.³²

In a 2005 multinational study, the annual cost-of-illness estimate for overactive bladder with or without UUI in the UK was over €1 billion, in Germany €1.2 billion in Sweden €333 million.³³ Routine care, nursing home admissions and lost productivity due to UUI were major contributors to the cost. This evidence demonstrates a substantial economic burden of UUI both on patients and on society.¹⁷

Figure 10.2 Diagrams of Pelvic Organ Prolapse



7.3 The NHS

The cost of incontinence and prolapse to the NHS is known to exceed £200 million annually,³⁴ which needs to be seen within the context of the Government's total expenditure. Total healthcare expenditure has risen from £81.4 billion in 2002 to £144.5 billion in 2012. Health expenditure per capita in England has risen from £1,712 in 2008/09 to £1,912 in 2012/13.³⁵ Bearing in mind that in 2014 the cost of managing incontinence per capita in the NHS was £248 in women affected and the total allocated was £1,912, it accounted for 13% of per capita health expenditure in these women.^{34,36}

However, this figure is unlikely to capture all the healthcare and individual costs of incontinence:

- In the UK in 2004, the cost of managing adults in the community with incontinence was £425 million.³⁷
- A variety of pads and pants have been used as a coping strategy but the costs can be high, both to the NHS and to the patient.^{38–40} Figures from the NHS supply chain, representing an estimated 75% of the acute and 55% of the community female incontinence pad market, indicate that overall spending (men and women) on incontinence pads was £29.6 million from February 2014 to January 2015.⁴¹
- Sampled data on 1,074,576 women aged 18 and older from the Clinical Practice Research Datalink showed that 21,692 (2.0%) of women were prescribed the anticholinergics darifenacin, fesoterodine, oxybutynin, propiverine, solifenacin, tolterodine or trospium for overactive bladder +/- UUI (termed 'bladder instability' in this dataset), in financial year 2014/2015. This represented a total annualised drug cost of £3,884,074 and an average annual drug cost of £179 per treated woman.⁴²

8. Rationalising treatment

8.1 Developing a strategy for life

Improvement in the incontinence and prolapse situation for women in England is likely to require a change in approach; young girls and women need to be made aware of the likelihood of developing pelvic floor dysfunction and then they could be educated in how to reduce the chances of it occurring and how to treat symptoms when they arise. If they do occur, a patient-centred approach to treatment plans should be adopted, starting as soon as symptoms begin in order to stave off worsening problems in later years, and it could also reduce the impact of pelvic floor dysfunction.

8.2 Management principles

Management of incontinence is determined by the type. The usual approaches are as follows:

- Advise women with urinary incontinence or overactive bladder (urgency) and who have a BMI >30 to lose weight.
- Stress urinary incontinence – pelvic floor muscle rehabilitation physiotherapy, anti-incontinence devices, pharmacotherapy in some cases (though not usually used) and surgery such as mid-urethral tapes/meshes or bladder neck suspension procedures.
- Overactive bladder UUI – behavioural modification such as fluid control, changes in diet to avoid irritative food types, pelvic-floor muscle exercises, medications, Botox injections to the bladder and more recently posterior tibial nerve stimulation. Spinal stimulation implants are also used in severe cases.
- Mixed incontinence – behavioural modification, physiotherapy, anticholinergic drugs, beta-sympathomimetic drugs and surgery.
- Overflow incontinence – behavioural modification, catheterisation regimens and surgery.
- Functional incontinence – treatment of the underlying cause.⁴³
- Faecal incontinence – pelvic floor physiotherapy, medication, behavioural modification, rectal irrigation and toileting aids such as anal plugs.
- The use of topical oestrogens in oestrogen deficiency states may also be helpful.

In general, the first choice for treatment is the least invasive, with the least number of potential complications for the patient. Examples of non-invasive treatments include lifestyle advice, behavioural modification, pelvic floor physiotherapy and medication. Intravaginal oestrogens for the treatment of overactive bladder symptoms may be useful in postmenopausal women with vaginal atrophy. However, such treatments may not give the best outcome in all situations. In specific situations, surgery may be indicated in managing urinary incontinence. Absorbent products, handheld urinals and toileting aids should not be considered as a treatment for urinary incontinence, but they do play a supportive role in continence care and should be used appropriately.⁴⁴

Treatment for prolapse depends on the type, but the broad principles of treatment are lifestyle changes, behavioural modifications, pelvic floor physiotherapy, the use of devices such as vaginal pessaries and, lastly, surgery.

9. Prevention

9.1 Raise awareness and education in women

A lack of awareness about incontinence and other aspects of pelvic floor dysfunction in the general population was evident in a cohort study of US women.⁴⁵ The association with ageing, obesity^{46–50} and childbirth seem to be the only widely known facts about incontinence.⁵¹ Less clear is its association with genetics/collagen type, constipation, neurological conditions,⁵² radical pelvic surgery,^{53–55} radiotherapy^{53,56–58} and female genital mutilation.^{12,59} By understanding the links with modifiable factors such as obesity and constipation and addressing them with early, simple advice, preventative strategies could be instituted.

9.2 Integration of community and social care

A significant amount of continence and prolapse management can be carried out within the community; the current pathway for women seeking treatment for pelvic floor dysfunction is through their general practitioner. An integrated approach, combining enhanced community services – linked with social support – and hospital care, has been described by the All Party Parliamentary Group on Continence Care's 2011 publication, *Commissioning on Continence*. This group constructed a prevention pyramid (see Figure 10.3)⁵⁴ which illustrates measures for improving continence care in the UK.⁶⁰ The role of other healthcare providers in triaging and treating women and in providing integrated services could be evaluated to meet some of the highlighted areas. Projects are being piloted to allow women to self-refer to physiotherapy clinics for treatment by the Chartered Society of Physiotherapy.⁶¹

9.3 Enhancing the role of physiotherapists

Physiotherapy is by far the most cost-effective intervention for preventing and treating incontinence and prolapse.³⁶ In a study involving 14 European nations, information on the incontinence resources used was gathered on all adult women seeking treatment for urinary incontinence (n=9847). It was found that conservative treatments, particularly pelvic floor muscle exercises, were more commonly used in patients in the UK and Ireland. GPs in the UK instituted care with mean total UI-related costs of £260 per patient. In other countries, the use of protective pads was more common, costing £375–£480 per patient, with treatment by specialists and GPs.³⁶

Physiotherapy may be used as a preventative and therapeutic strategy for women from adolescence onwards and clear guidelines on behavioural interventions, such as losing weight and treating constipation to reduce impact on the pelvic floor, can be instituted.⁶² Physiotherapy helps people affected by injury, illness or disability through movement and exercise; manual therapy, education and advice. These modalities are all employed by the specialist pelvic floor physiotherapist to treat patients with pelvic floor dysfunction.

Other conservative therapies, such as vaginal pessaries (which offer symptomatic improvement for women with pelvic organ prolapse or urinary incontinence) are encouraged, as they are accessible in the community setting. They are less expensive than specialist care in hospitals and can be used by appropriately trained nurse practitioners, continence advisers or physiotherapists.⁶³

9.4 Enhancing the role of continence nurses

Continence nurses or continence advisers use a wide range of diagnostic tools to reach a definitive symptomatic/symptoms-based diagnosis, including quality-of-life questionnaires and frequency–volume charts. They can offer advice which may improve or cure bladder/bowel/sexual problems.⁶⁴ Nurse-led continence services or continence adviser clinics provide an integrated bladder and bowel dysfunction service to patients registered within community practices. These services offer four main activities for patients:

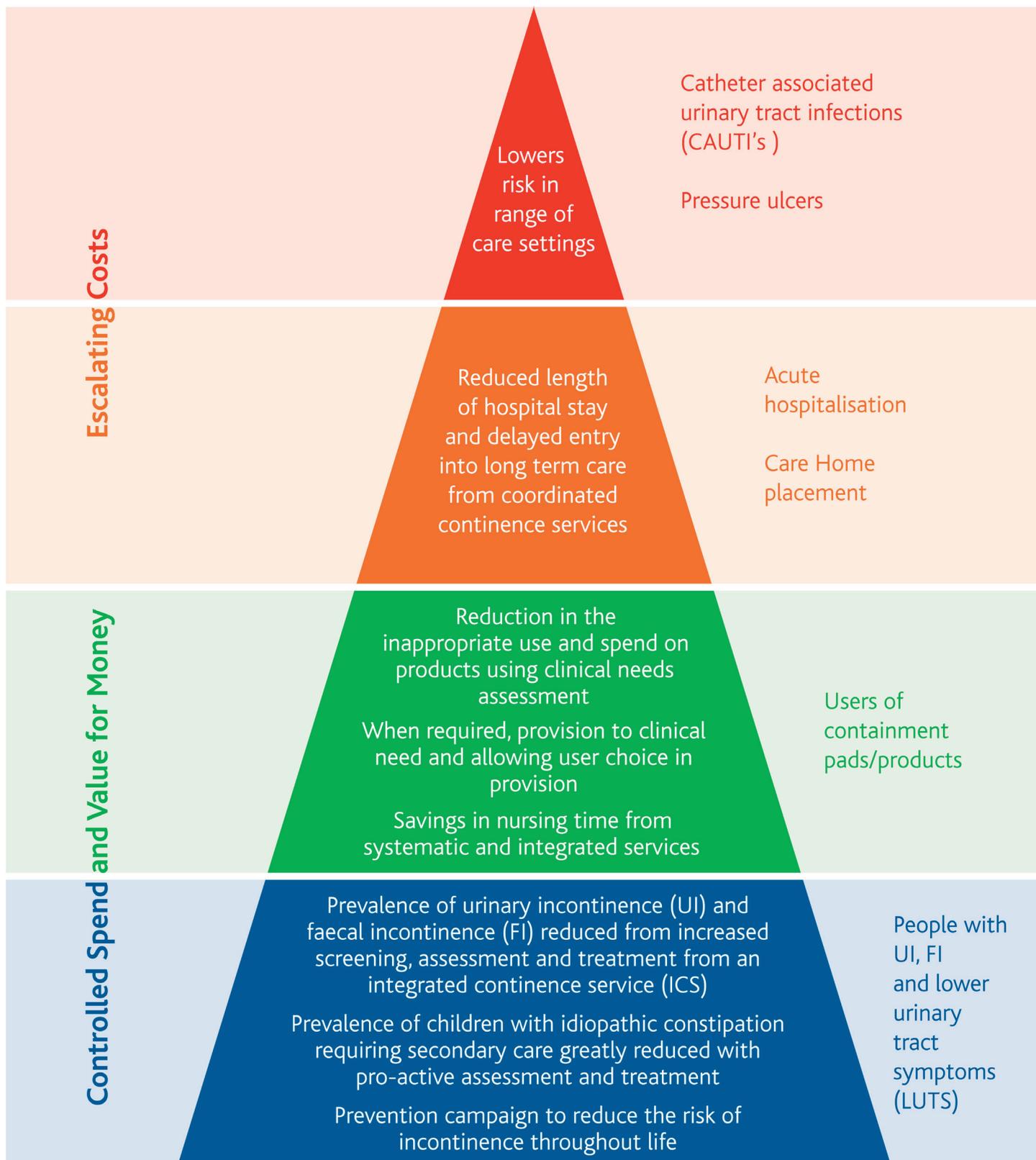
1. Community-based specialist continence and bladder and bowel dysfunction clinics – aimed at continence promotion, and improvement or resolution of the pelvic floor complaint.
2. Provision of NHS incontinence products such as pads, pants or catheters for patients unsuitable for interventional treatment, or who have failed to respond to intervention (including residential homes for older people).
3. Provision and management of prolapse and continence using aids, such as vaginal pessaries.
4. Telephone advice, education and support for the local community and healthcare/social care services.

Nurse and/or physiotherapist-led models of care can be appropriate in conservatively treating and preventing bladder/bowel/sexual dysfunction. However, these require evaluation in England.

Case study – Postpartum stress urinary incontinence

A 33-year-old woman presented with a history of stress urinary incontinence to her GP, following the birth of her first child. She was seen within a local continence service and advised on behavioural strategies such as monitoring her fluid intake, reducing caffeine and performing pelvic floor physiotherapy. By following this advice she was able to maintain continence until she had completed her family at age 37. Thereafter, she realised that she was having increasing problems despite conservative measures which had served her well for several years. At this point she was referred to hospital to consider other options, including surgery.

Figure 10.3 Incontinence Prevention Pyramid



Source All Party Parliamentary Working Group for Continence Care Report (2011)

10. Conclusion

Incontinence and prolapse have well-defined aetiological profiles and may be amenable to preventative strategies, which could begin with educating the general public, in particular women and girls. Conditions associated with pelvic floor dysfunction have significant impact on the individual, the NHS and society. By instituting preventative strategies, it is possible to reduce such impact and improve the individual's quality of life.

Opportunities for direct access to conservative treatments may obviate the need for women to attend GP surgeries and hospitals. The costs to the NHS may then be reduced and access to care enhanced but, more importantly, women could be empowered to prevent incontinence and prolapse in the first place.

In those for whom conservative therapy may not have been effective, there may be a role for the following: intravaginal oestrogen therapy (for those with post-menopausal urogenital changes), pharmacotherapy (for those with overactive bladder symptoms) and surgery (for those with complex bladder/bowel dysfunction and/or prolapse). However, these should only be used as a last resort.

11. Author's suggestions for policy

- Commission research to establish the prevalence of urinary incontinence, faecal incontinence and prolapse in England, in order to guide service provision.
- Establish public health and clinical management programmes to improve awareness of urinary incontinence, faecal incontinence and prolapse and highlight the need for prevention, early diagnosis, self-help and management.
- Introduce public health programmes promoting pelvic floor education in achieving good bladder and bowel habits.
- Evaluate nurse-led clinics, community continence services and physiotherapy referral services that patients can access directly.
- Establish high-quality tertiary referral centres that can provide the necessary multi-disciplinary approach to women with complex or recurrent problems who have failed to respond to local/conservative intervention.

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Chapter 11

Women's cancers

Chapter lead

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1. Key statistics

- Half of all women will develop a cancer at some point in their lifetime.
- In 2012, 172,563 women in England were diagnosed with cancer, and just over a third of the cancers diagnosed were 'women's cancers', including (in descending order of prevalence of diagnosis) breast, uterine, ovarian/peritoneal, cervical, vulval and vaginal cancers.
- A quarter of women diagnosed with women's cancers in 2012 are likely to die from their cancer within five years of their diagnosis.
- In 2013, 261,205 women died – 26.2% of these deaths were due to cancers, of which 6.5% were 'women's cancers'.
- Cancer survival is a key metric of the efficacy of a healthcare system. In the UK, one year survival for the most common stage at diagnosis of ovarian cancer (stage III) is 70.3% compared with 77.5% in Norway and 82.3% in Canada, which have a similar stage distribution.
- The majority of uterine cancers (>70%) are grade 1/2 endometrioid cancers (type 1 tumours) associated with obesity and oestrogen excess. It is predicted that the number of new diagnoses in the UK will rise to around 11,000 in 2030.

2. Overview

This chapter will focus on ovarian cancer, uterine cancer and cervical cancer, including those who are not served by the screening or vaccination programmes.

The goals of modern cancer care are to

- reduce the incidence of cancer
- diagnose cancer at the earliest stage possible
- deliver optimal treatment for maximal survival benefit
- reduce morbidity.

Cancer survival is a key metric of the efficacy of a healthcare system.¹ Survival in England and the United Kingdom as a whole is lower than in comparable countries – particularly for ovarian cancer.^{1, 2, 3, 4} For example, if survival rates for those diagnosed with women's cancers between 1995 and 1999 had matched the best countries in Europe, 13,912 deaths could have been avoided.⁵

Outcomes for breast cancer have been steadily improving and the survival gap between the UK and better performing countries appears to be closing.³ This is likely to be due to improved diagnosis, better treatments and efficient screening. Since 2010 any patient with breast symptoms is seen in a rapid access clinic, whereas for other tumour sites rapid access clinics are reserved for those perceived to be at high risk of cancer. Debate continues in the scientific community concerning the ages for breast screening and its role, but this is well covered by other publications.⁶ Breast cancer is also well resourced in terms of research, patient information, charitable funding and support.⁷

Vulval and vaginal cancers are rare (1,262 cases were diagnosed in 2012), and compared with other European countries our survival rate is similar.²

Thus women with breast, vulval and vaginal cancers in England, when compared with other high income countries, are at less risk than those with ovarian, uterine and cervical cancers.

Cervical cancer has seen enormous reductions in incidence and mortality since the introduction of the screening programme, but there remain groups of women who are at risk of this largely preventable cancer. Ovarian cancer has low survival in absolute terms and also relative to other countries. Uterine cancer has an increasing incidence both due to the ageing population and the obesity epidemic.⁸

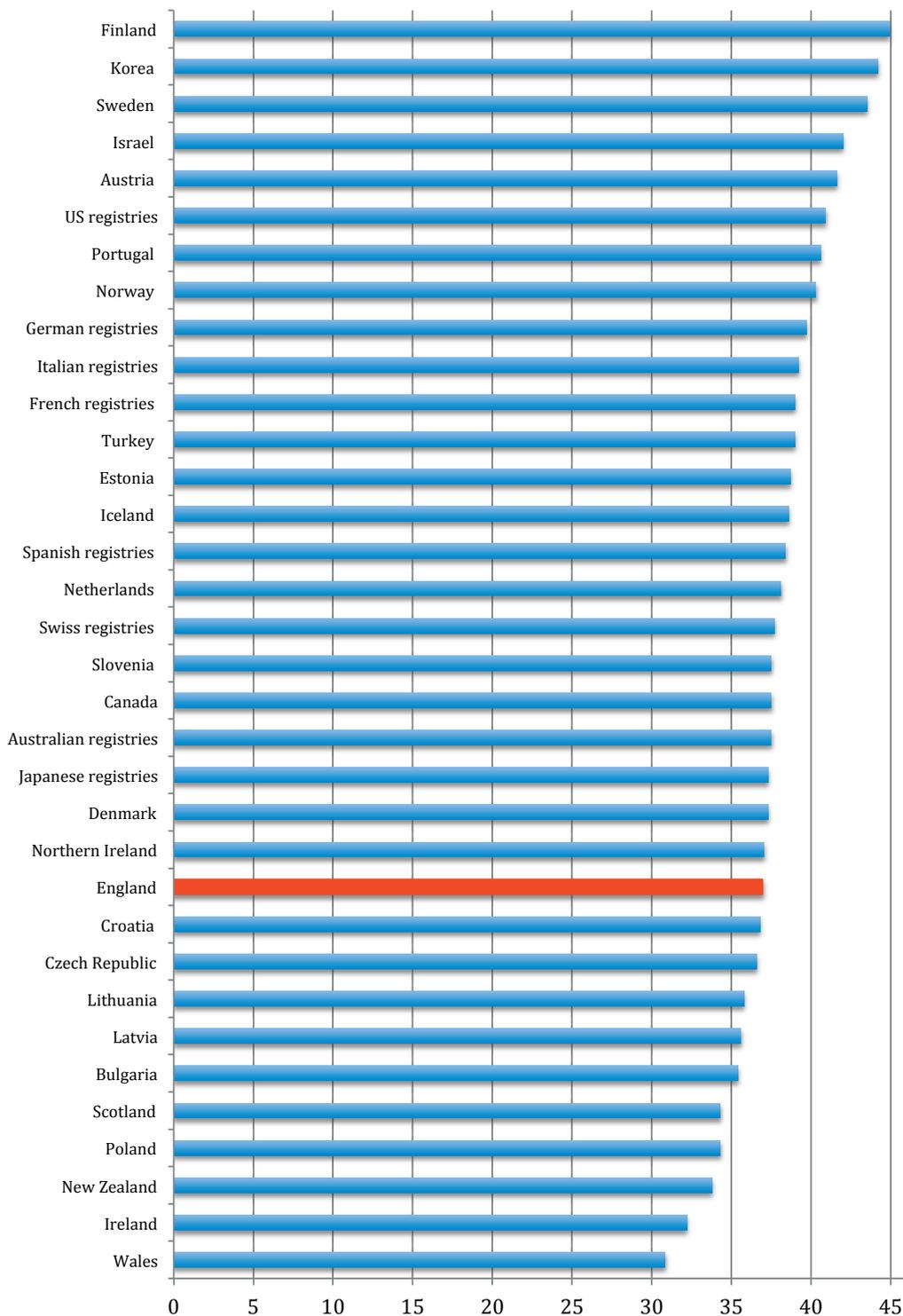
3. Ovarian cancer

Ovarian cancer is the second most common gynaecological cancer and the most lethal: 6,483 women in England were diagnosed with ovarian cancer in 2012 and there were 3,988 deaths in 2013.^{9, 10} Survival in England and the UK is among the lowest in the OECD nations, with five year net survival around 36%.³

Early diagnosis and screening

Ovarian cancer has been called 'the silent killer' as most patients (>70%) present with advanced disease with non-specific symptoms.¹¹ This has led to awareness campaigns to increase the diagnosis of early stage ovarian cancer and improve survival. Unfortunately evidence that early diagnosis improves outcomes is lacking. This is probably due to the most common form of ovarian cancer (type II) typically

Figure 11.1 Five year net survival ovarian cancer rate 2005–09



Source Allemani et al 2014

presenting with intra-abdominal spread, and ovarian cancer symptoms which are either incidental or due to disseminated disease.^{12, 13}

Table 11.1 Types of ovarian cancer

Type 1 (25%)	Type 2 (75%)
<ul style="list-style-type: none"> ■ Low-grade serous ■ Low-grade endometrioid ■ Clear cell ■ Mucinous ■ Transitional 	<ul style="list-style-type: none"> ■ High-grade serous ■ High-grade endometrioid ■ Undifferentiated ■ MMMT/carcinosarcoma

(MMMT – Malignant mixed Mullerian tumour)

The less common type I ovarian cancers usually present at an early stage with a pelvic mass and, as they follow a more indolent course, are more amenable to early diagnosis.

There is no evidence that population screening for ovarian cancer reduces ovarian cancer mortality; however, it may result in more complications from unnecessary surgery.¹⁴ There is an ongoing UK population-based trial of screening for ovarian cancer whose data are reaching maturity.¹⁵

Improving diagnosis of patients with non-specific symptoms

Early diagnosis initiatives may not increase the proportion of early stage ovarian cancer diagnoses due to the adverse tumour biology of ovarian cancer. Initiatives to promote early diagnosis are, however, important for cancer in general and they may help expedite the diagnosis and treatment of advanced stage ovarian cancer. However, we feel that attempting to educate GPs so that they suspect ovarian cancer early is an unachievable aim for three reasons:

- Ovarian cancer is a very rare disease in primary care (about one case every five years per GP).
- It is debatable whether early ovarian cancer is ever associated with the classic symptoms of the disease (abdominal bloating, non-specific abdominal discomfort). Signs of early ovarian cancer include pelvic discomfort and the finding of a pelvic mass that may, or may not, be associated with symptoms.
- When patients do have the classic abdominal symptoms they usually have advanced disease.¹²

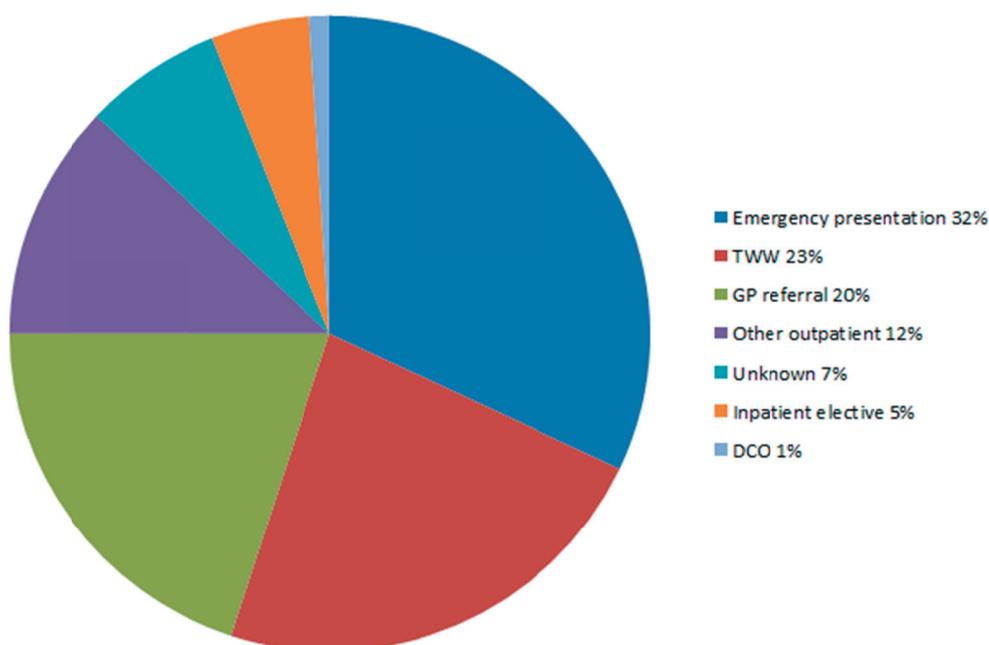
We recognise that expecting GPs to perform pelvic examinations to detect early disease (either benign or malignant) in their routine clinics is a considerable challenge, if not unachievable. Greater availability of pelvic examination and assessment in the community, eg community gynaecological clinics or direct access transvaginal ultrasound, would require review of referral pathways.

A recent survey reports that with an identical clinical vignette representing an ovarian cancer patient, fewer than 40% of GPs in England would refer or investigate compared with over 60% in Australia and Canada – both countries with better ovarian cancer survival. Furthermore, only a third of GPs in England were able to get specialist advice within 48 hours compared with the other two countries.¹⁶

The existing pathways for suspected cancer referral in England do not reflect the actual route by which women receive a diagnosis of ovarian cancer; one third of patients are diagnosed as an emergency compared with only 23% via rapid diagnostic clinics.¹⁷

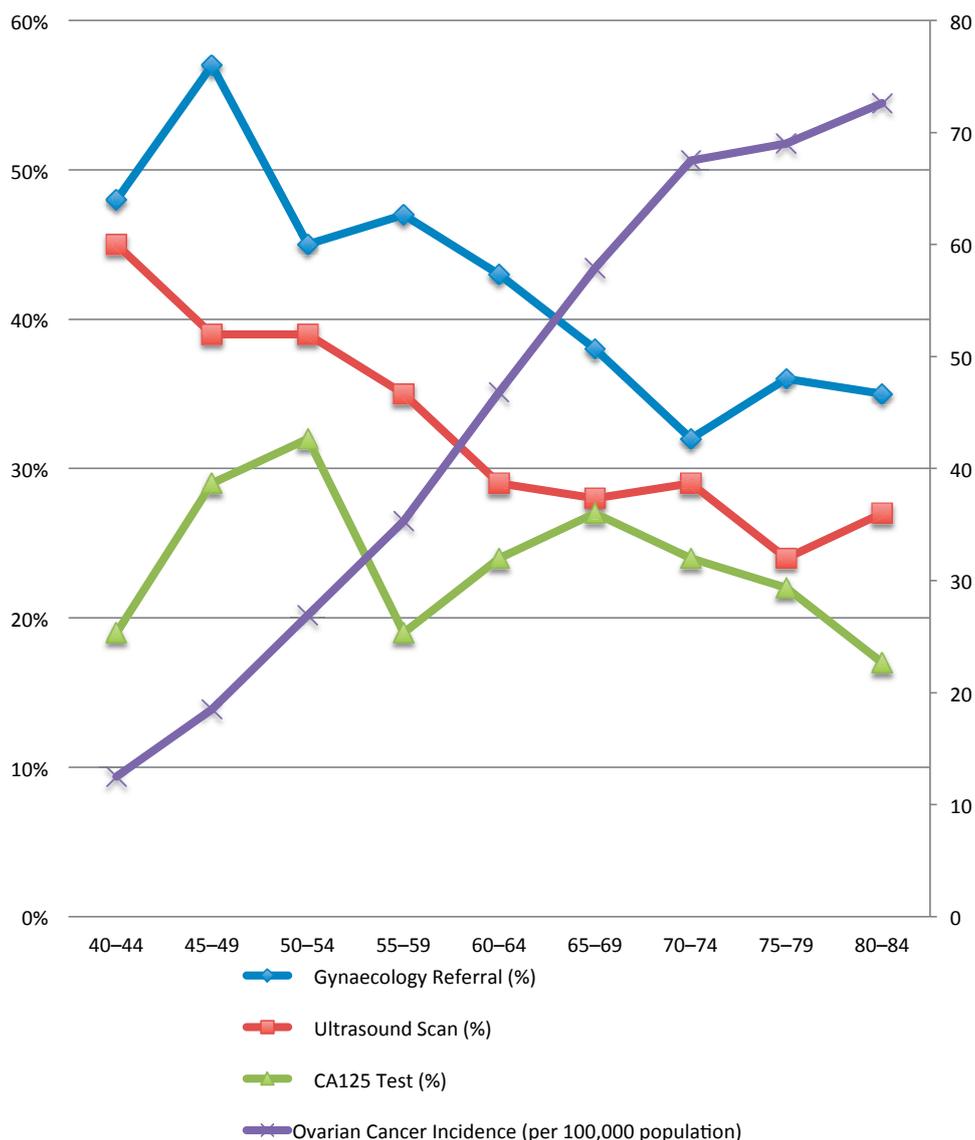
Figure 11.2 Proportion of ovarian cancers diagnosed by route

TWW = Two Week Wait
DCO = Death Certificate Only



Source Elliss-Brookes et al. 2012

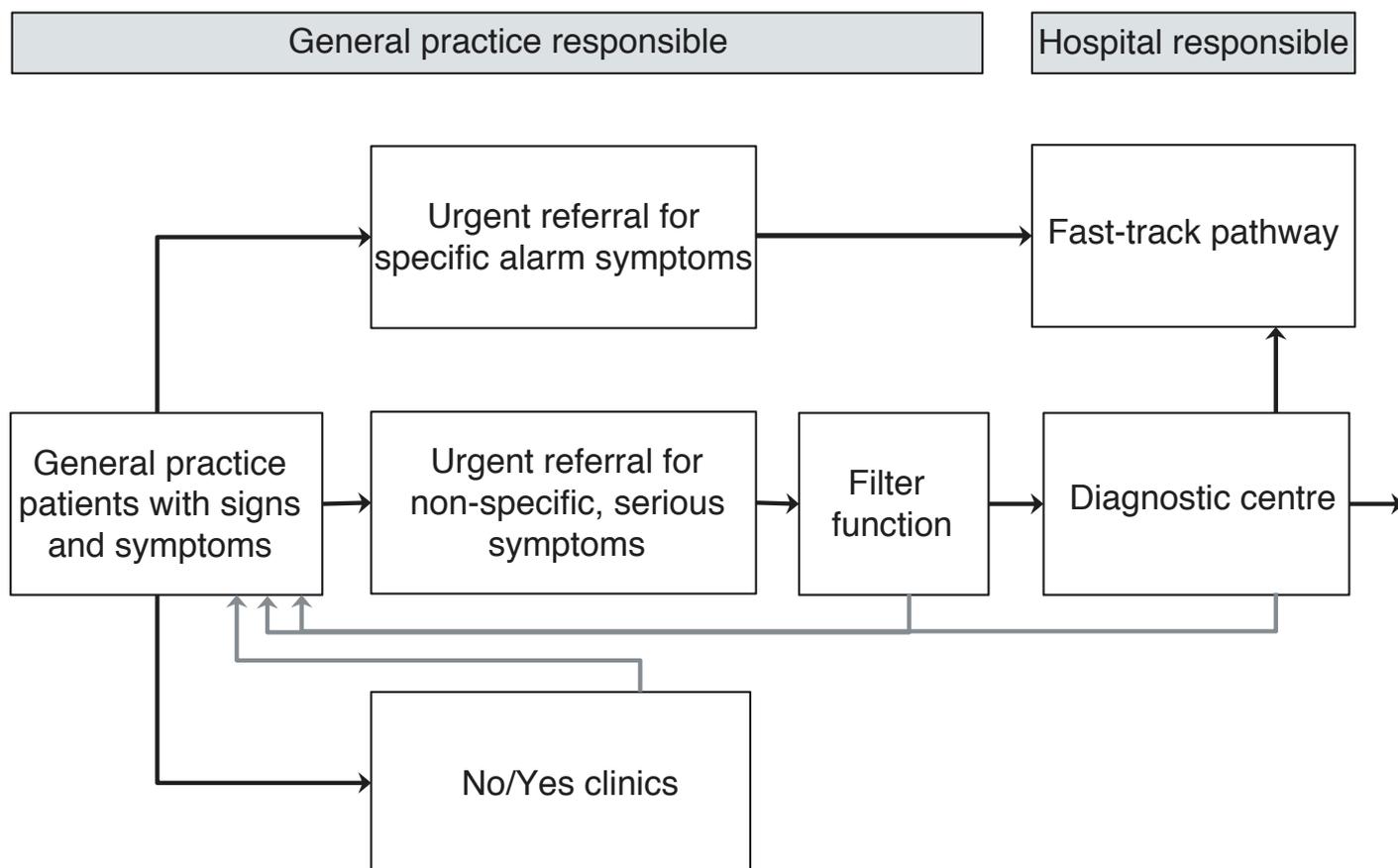
Figure 11.3 Proportion of ovarian cancer cases by age band (%) having gynaecology referral, CA125, or pelvic ultrasound investigation for ovarian cancer in the year before diagnosis plotted with ovarian cancer incidence per 100,000 population



Most cancer patients, especially those with ovarian cancer, are not diagnosed via urgent referral pathways. Pathways for the assessment and investigation of non-specific abdominal symptoms may allow rapid assessment, diagnosis and treatment of both advanced ovarian cancer and other diseases – both malignant and benign. Denmark, like England, has low cancer survival but has successfully implemented early diagnosis strategies and has improved its cancer survival at a greater rate than England.¹⁹

One component of this is the Danish 'three-legged strategy' whereby GPs can refer to: 1) an urgent referral pathway; 2) No/Yes clinics – where GPs can have rapid access to investigations such as colonoscopy, CT or ultrasound; and 3) a diagnostic centre for assessment and investigation of non-specific symptoms such as weight loss, fatigue, unspecific pain, nausea, 'problems with general health' and a GP's 'gut feeling'.²⁰ Interestingly, 'gut feeling' was one of the strongest predictors of the diagnosis of cancer in primary care in a Danish study.^{21, 22}

Figure 11.4 The structure of the Danish three-legged diagnostic strategy for ovarian cancer



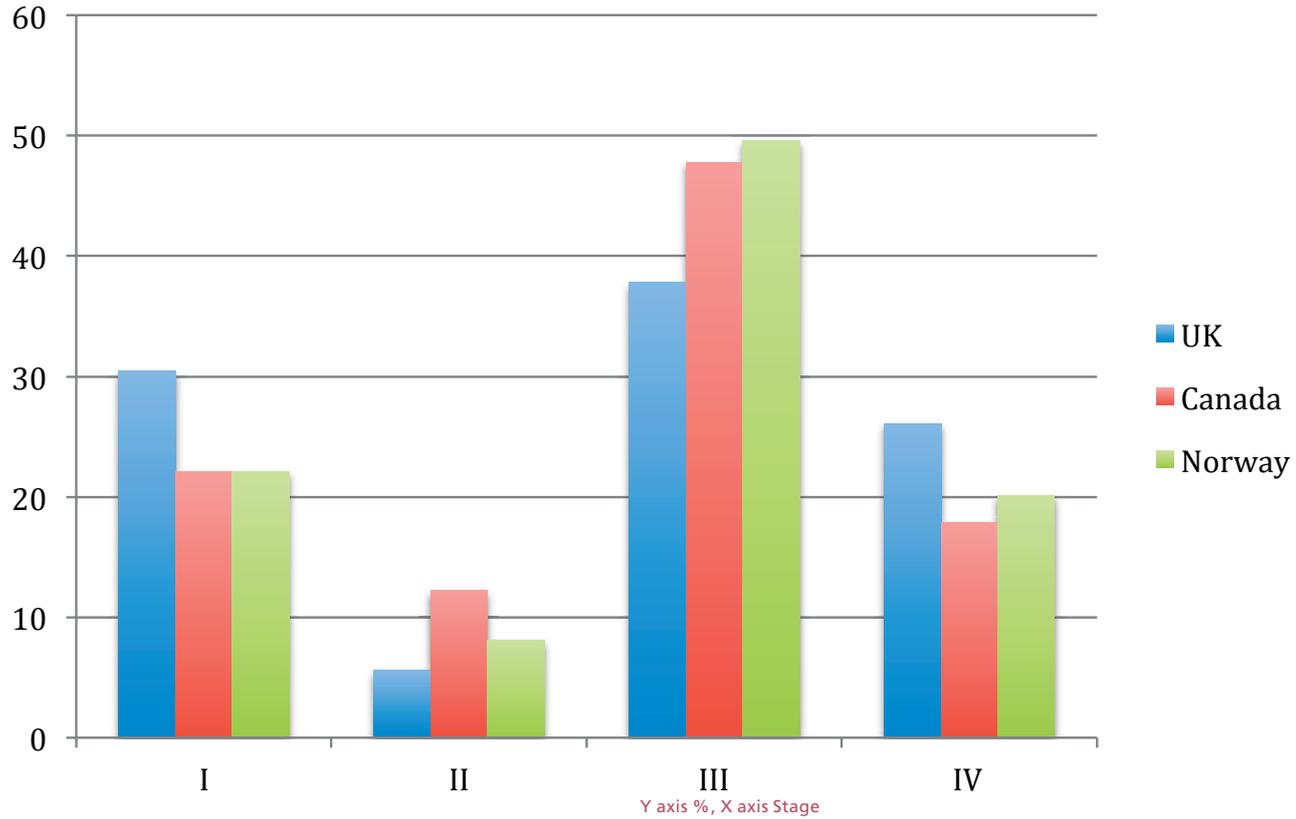
Treatment of ovarian cancer

The relatively low survival rate in the UK does not appear to be due to there being more patients with advanced stage disease at diagnosis but the lower stage-specific survival of patients with stage III and IV ovarian cancer. For example, in the UK one year survival for the most common stage at diagnosis of ovarian cancer (stage III) is 70.3% compared with 77.5% in Norway and 82.3% in Canada, which have a similar stage distribution.⁴ The UK has more stage I/II patients (36.1% vs 34.3% and 30.2%) and fewer stage III/IV (63.9% vs 65.7% and 69.7%) patients than Canada and Norway respectively.

As diagnosis of ovarian cancer at an early stage does not appear to be as effective in improving survival when compared with cancers with clear symptomatology and relatively easy diagnosis such as breast, uterine and cervical cancers, it is likely that treatment variation is the main contributor to low survival in the UK.

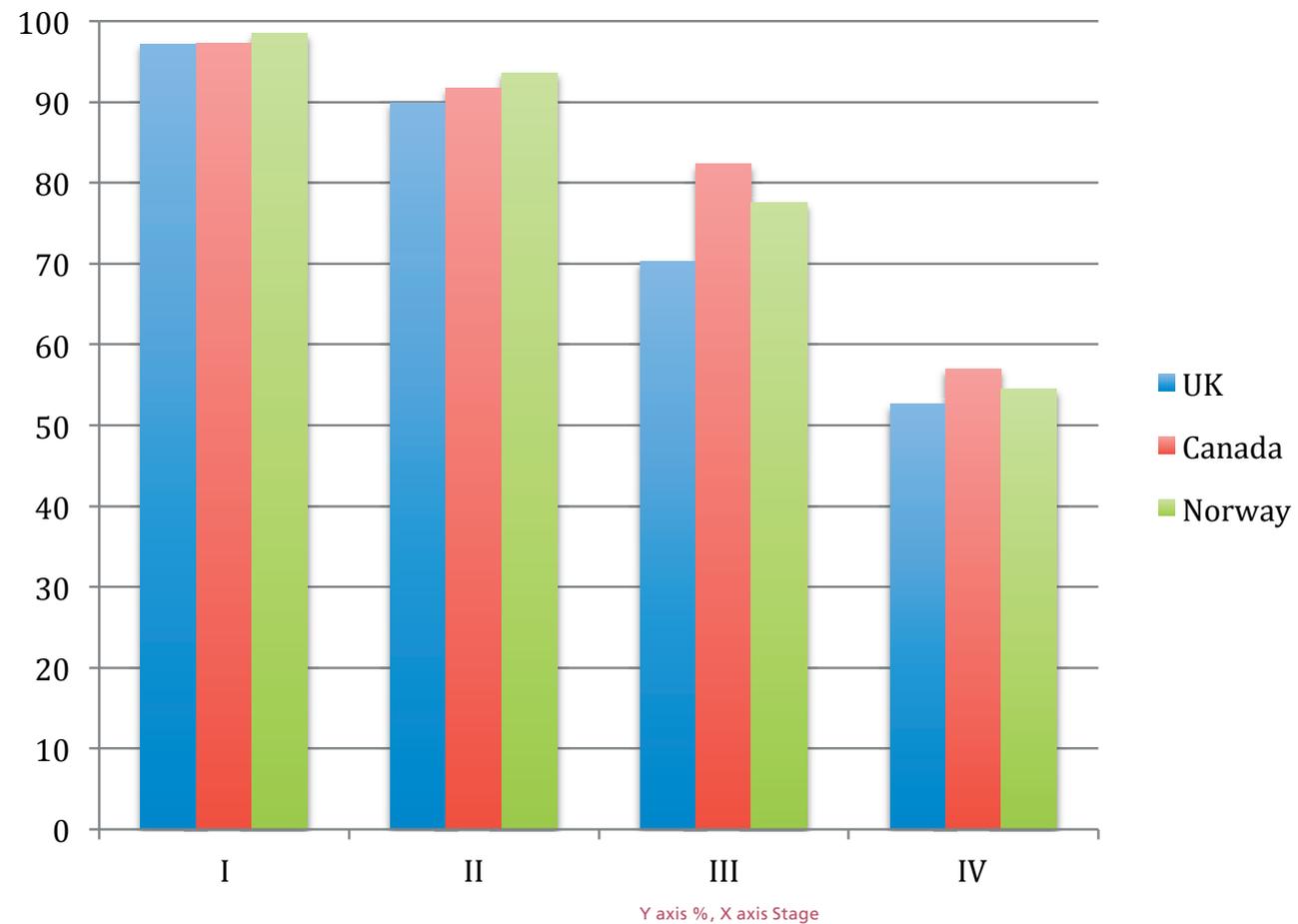
The most important predictor of ovarian cancer survival in advanced ovarian cancer disease is the volume of residual disease after primary or delayed primary debulking surgery: those with no residual disease have the best prognosis, an observation that has been consistent in all clinical trials since the mid 1970s.^{23, 24, 25} This is therefore the goal for surgical treatment. Achieving this goal is a major challenge for the NHS and there is some urgent need to address this. There are three elements that contribute to achieving no residual disease at surgery: patient factors; the surgeon; and the organisation of surgical and hospital services within the NHS.

Figure 11.5 Stage distribution – ovarian cancer (Maringe et al. 2012)



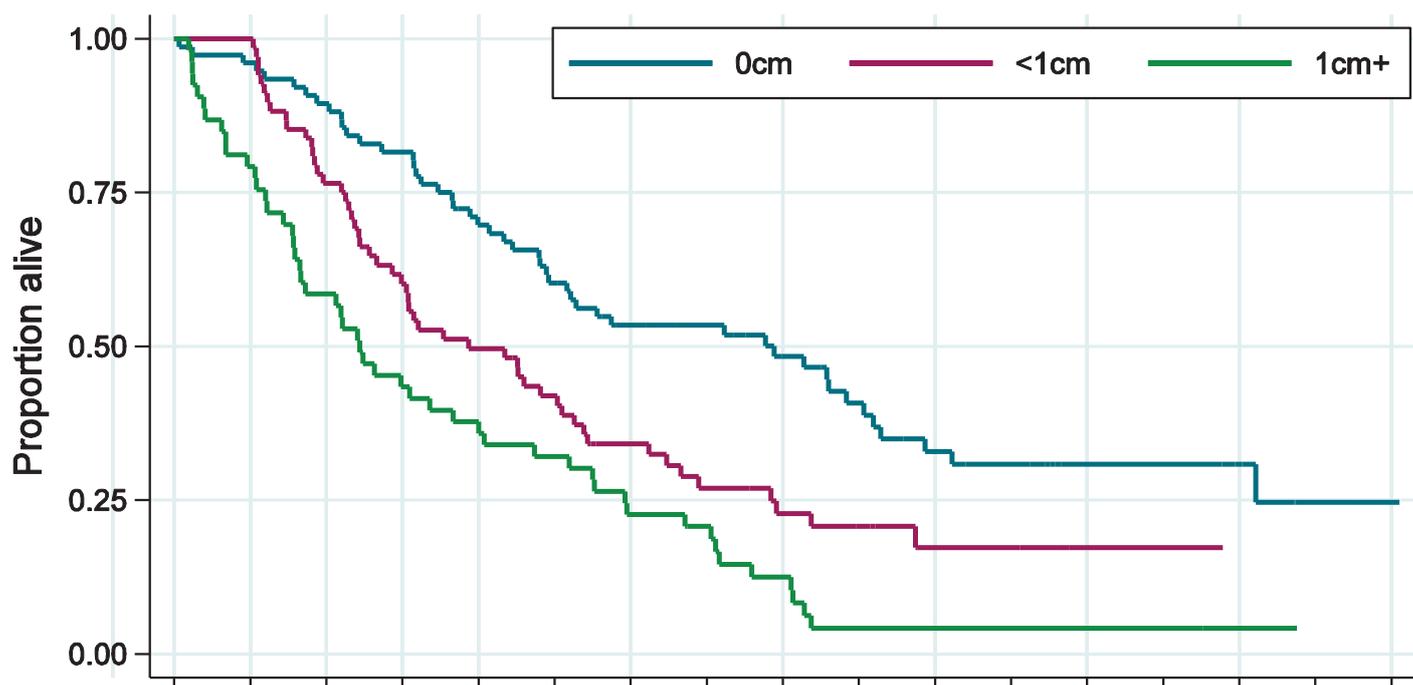
Source Maringe et al. 2012

Figure 11.6 Stage specific one year net survival (Maringe et al. 2012)



Source Maringe et al. 2012

Figure 11.7 Survival and volume of residual disease (CHORUS data, 98% of patients from UK) (Kehoe et al. 2015)



Source Kehoe et al. 2015

Patient factors

The abdominopelvic surgery required to clear patients of macroscopic (visible) disease often involves multiple visceral procedures including small and large bowel resections, diaphragmatic peritoneal stripping, and para-aortic and pelvic lymphadenectomy. Patients with increased co-morbidity and/or older people may not be able to tolerate these procedures safely and are less likely to receive guideline-compliant care.²⁶ Major resection rates for ovarian cancer are lower in older patients – 26% in women aged 80 and above compared with 63% in those aged 60–69.²⁷ In 2012, a third of ovarian cancer patients were aged over 75; this group had the lowest survival rate and this appears to be mainly due to surgical under-treatment.

Surgeon factors

The majority of patients present with advanced disease and they often have tumours in the upper abdomen. In order to completely remove all visible ovarian cancer, complex surgical procedures are often required. It is encouraging that since the *Improving Outcome Guidance* was published in 1999 there has been increased centralisation of ovarian cancer surgery in England. In 2009, 36% of patients received surgery by gynaecologists who had received specialist training and were accredited by the General Medical Council compared with 5% in 2000 ($p < 0.001$).²⁸

Despite this, a recent survey of UK gynaecological oncology surgeons reported that over 70% of surgeons said that their patients did not receive diaphragmatic surgery and 22% did

not perform para-aortic nodal dissection – both factors are a major determinant of complete cytoreduction and improved survival.²⁹ Thus more than one factor has been identified, but the relative contributions of these factors to poor surgical outcomes remains to be established.

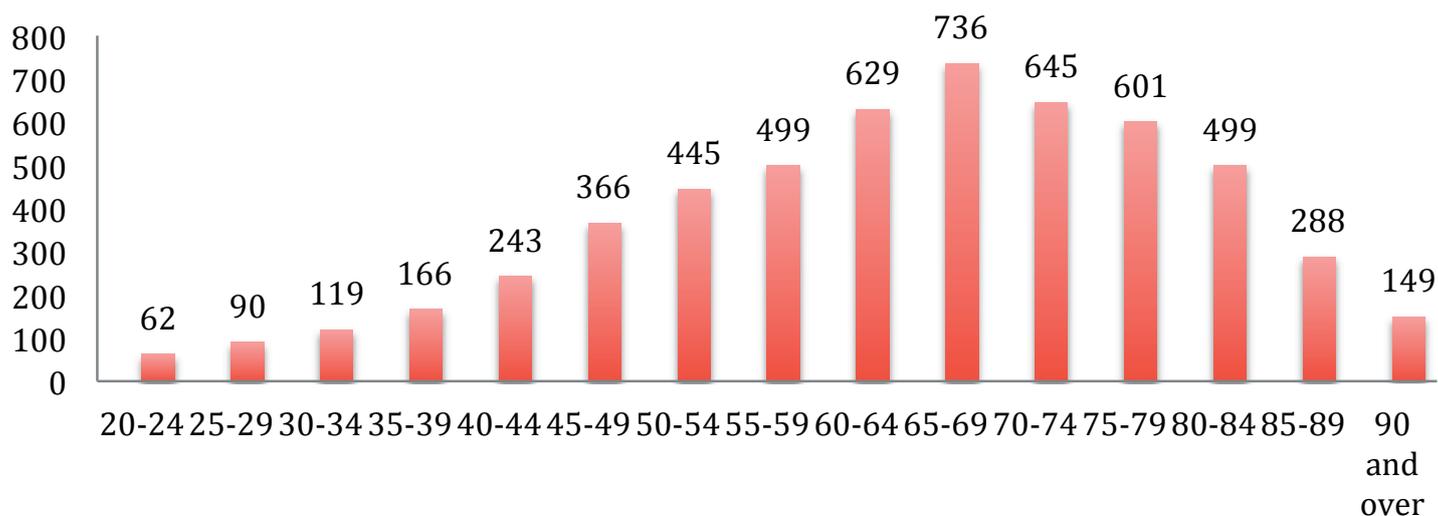
NHS cancer treatment pathways

The NHS Cancer Plan introduced national waiting time targets for cancer treatment, including surgery: 31 days from a decision to treat and 62 days from referral.^{30, 31} Since 2009/10 the number of patients referred for investigation or treatment of cancer has increased notably. The 85% operational standard has not been met since the fourth quarter of 2013/14. This suggests there is saturation of surgical capacity for cancer surgery. (See Figure 11.16.)

These targets are an important goal to help drive efficiency and speed to treatment but they can put pressure on a system and start to impair quality of care. This is particularly important for ovarian cancer surgery where in a UK setting high volume surgery is not associated with improved rates of complete cytoreduction.²⁹

Operating times appear to be a major predictor of outcome in the UK and in cross-country comparisons.^{29, 32} For example, the majority of UK surgeons (78%) report an average operating time for advanced ovarian cancer surgery of <3 hours with an average complete cytoreduction rate of 30.8%, compared with 54.3% for the remaining 22% of surgeons with average operating times of ≥ 3 hours.

Figure 11.8 Ovarian cancer diagnoses by age, 2012



The CHORUS study, 98% of participants in which were from the UK, randomised patients with advanced ovarian cancer to upfront surgery followed by chemotherapy or first line chemotherapy with surgery after three cycles. The median operating times were 2 hours in both arms of the trial and complete cytoreduction rates (ie no residual disease) were only 17% and 39% respectively. As 98% of the 552 patients accrued were from the UK these data give an insight into what some colleagues from abroad would regard as a fundamental deficiency in UK practice.^{33, 34} Studies from other countries with large series of patients with better complete cytoreduction rates and survival report median operating times twice those of the UK, approximately 4 hours.^{35, 36} The pressures on theatre capacity, intensive care bed availability and speed to treatment are likely to contribute to lower complete cytoreduction rates in England and lower surgery rates in older patients.

National audit

High-quality national audit can improve outcomes as has been shown for lung, bowel, head and neck, and oesophago-gastric cancers.³⁷ Since 1952 there have also been triennial audits into maternal deaths. A national audit of ovarian cancer is surely long overdue: in 2012 there were 143 times more gynaecological cancer deaths than pregnancy-related deaths in England (6,721 vs 47). Ovarian cancer accounted for more deaths than pregnancy overall and also in the child-bearing age group.

Most prognostic factors that are not stage related cannot be altered. Almost uniquely in cancer, the most important prognostic factor for advanced ovarian cancer outcome (residual disease after primary surgery) can be audited and improved, and positively impact on survival. Therefore improving the rate of optimal debulking should be a major aim and outcome measure for gynaecological cancer centres.

Figure 11.9 Percentage of ovarian cancer patients treated by a specialist gynae oncologist surgeon (2000–09)

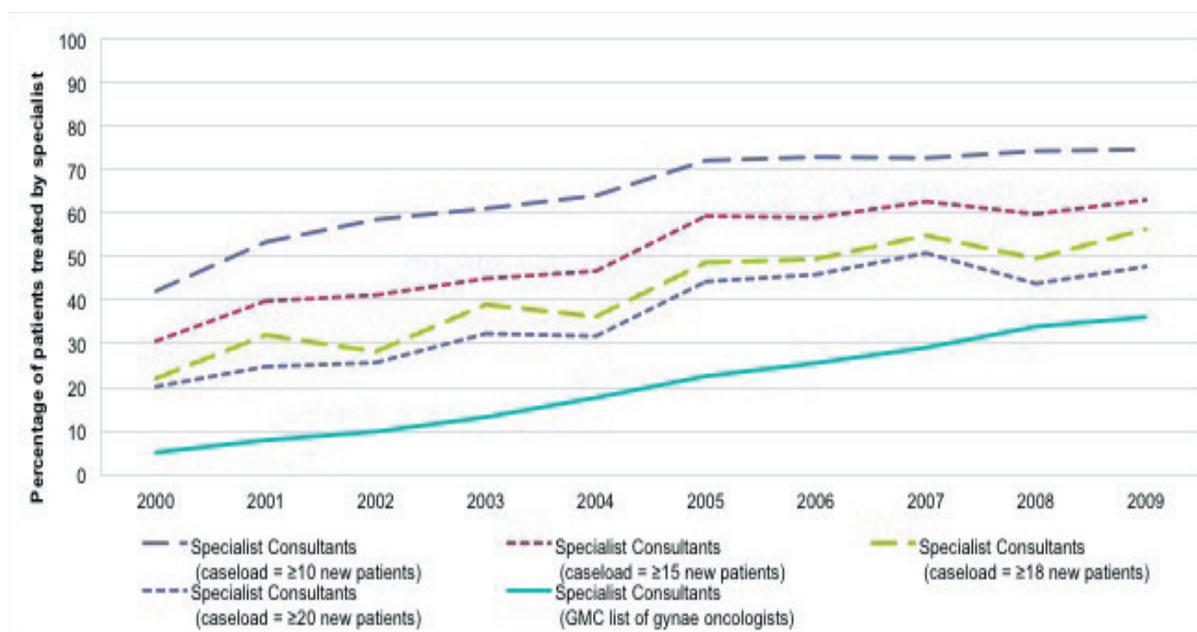
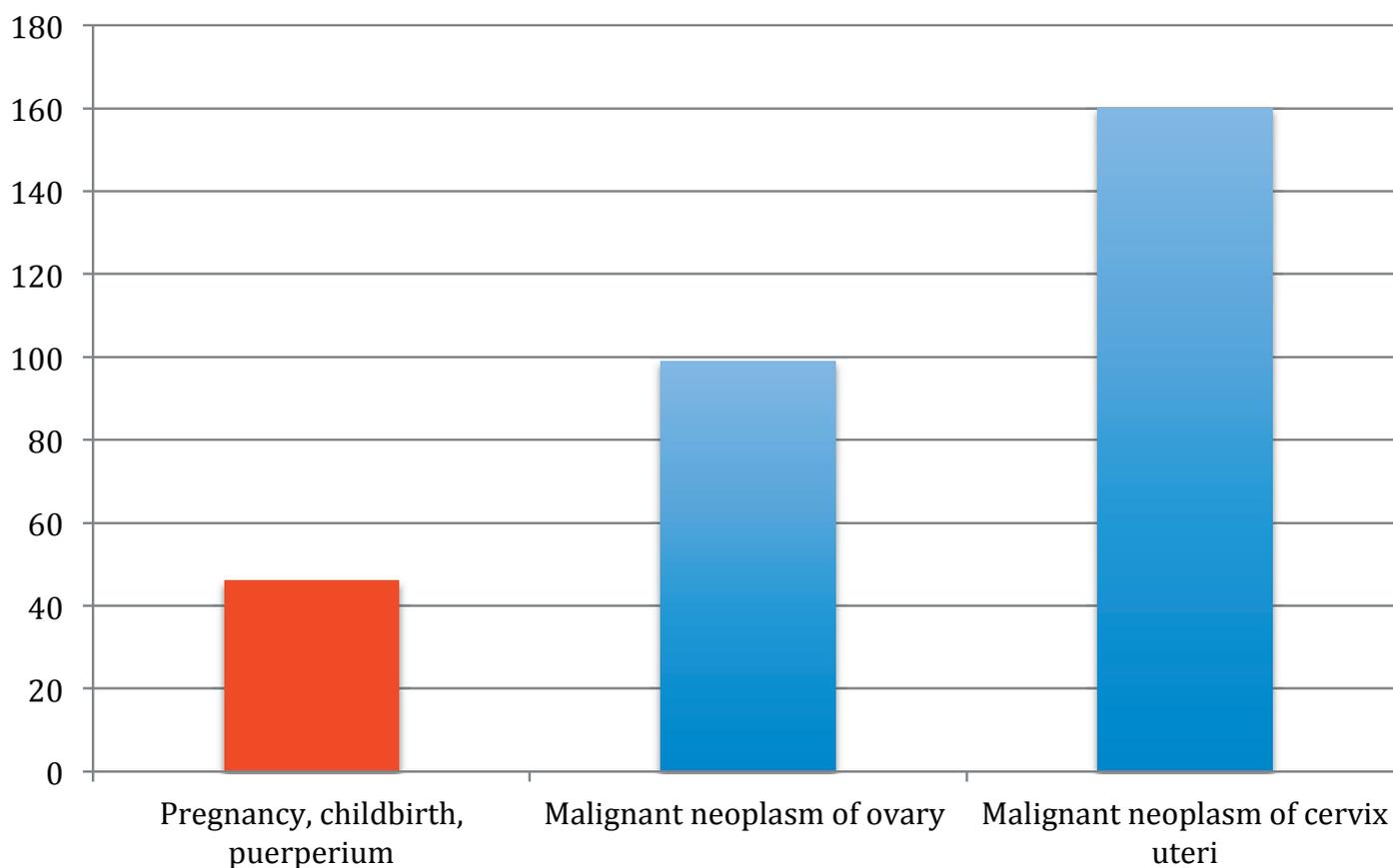


Figure 11.10 Causes of death in women under 45: maternal mortality vs ovarian and cervical cancer ('Deaths Registered in England and Wales (Series DR), 2013')



Source Maringe et al. 2012

Chemotherapy for ovarian cancer

Platinum plus taxane-based chemotherapy is the international standard of care for fit patients with advanced ovarian cancer. UK oncologists appear to be more conservative with their use of platinum-based combination chemotherapy than in some other countries, and are less likely to prescribe newer compounds.^{38, 39} Unfortunately, most patients will relapse and eventually develop resistance to chemotherapy.

The major developments in systemic treatments for cancer have been: maintenance therapy; immunotherapy; targeted agents; and, for ovarian cancer, intraperitoneal chemotherapy. None of these have yet demonstrated a major effect on overall survival in UK patients. Their impact has been incremental at best when compared with some other novel therapies for cancers, eg Herceptin for breast cancer and BRAF inhibitors for melanoma. There may be a future role for intraperitoneal chemotherapy in advanced ovarian cancer.⁴⁰

Box 11.1 Subtypes of ovarian cancer and personalised medicine

It is clear that the standard topographic description of ovarian cancer includes many different diseases of the ovary and fallopian tube that have variable responses to chemotherapy and surgery. For example, around 15% of ovarian cancers are associated with a BRCA mutation and these tumours show response to a novel targeted therapy – PARP inhibitors which can be used to maintain remissions (Wiggins et al. 2015; Ledermann et al. 2012).

Improvements in progression-free survival through maintenance therapy have also been demonstrated with VEGF-targeted agents, eg bevacizumab and pazopanib (Burger et al. 2011; Perren et al. 2011; du Bois et al. 2014).

Diagnostic services, including molecular profiling such as BRCA testing, allow not only the identification of patients who may benefit from novel therapies but also, in the case of BRCA testing, an opportunity for hereditary predisposition to be identified and prophylactic measures offered.

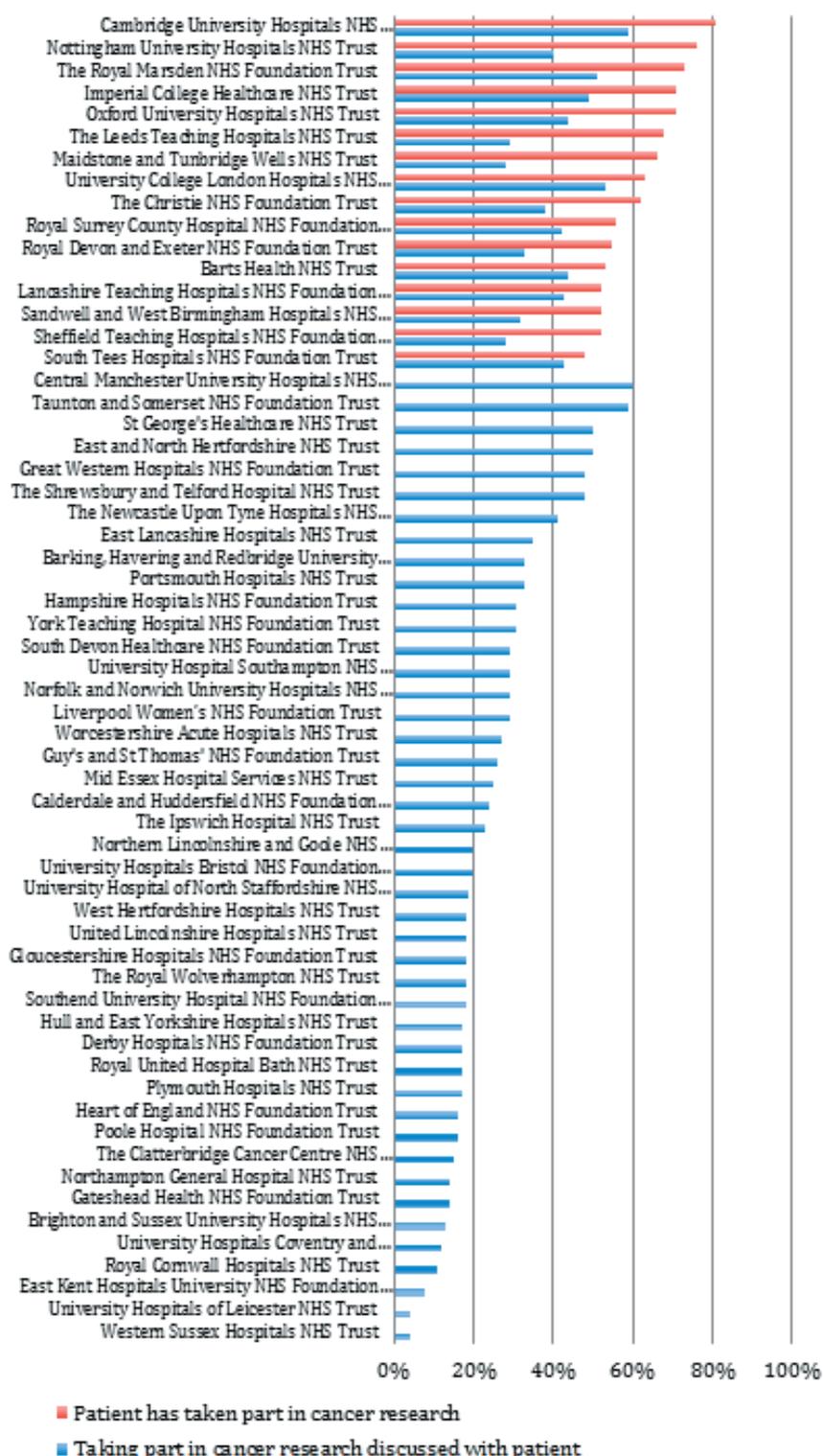
Clinical trials

Access to clinical trials helps to ensure that guideline-compliant treatment is being offered as all patients in a trial must adhere to a strict protocol of treatment. Clinical trial participation for this group of patients is low in England and in a recent survey of 3,241 gynaecological cancer patients only 28% of patients recalled being invited to take part in research, and patients from only 16 trusts recall having taken part in cancer research.⁴¹

Cancer drugs

Access to and use of new systemic therapies is a recognised challenge in the UK. There are no data on the impact of this in relation to overall survival. However, the new Systemic Anti-Cancer Therapy Dataset (SACT) may allow us to start assessing the real usage of different agents, particularly at relapse, and their impact on survival.⁴² It will also allow regional and centre variation to be examined and whether these variations cause survival differences.

Figure 11.11 Gynaecological Cancer research discussed with patient, patient has taken part in cancer research (National Cancer Patient Experience Survey 2014 National Report)



The current funding model of the healthcare system in England is unlikely to allow all patients who might benefit access to novel expensive treatments and prioritisation is a major challenge for healthcare professionals, policymakers and industry. For example, the Cancer Drugs Fund was introduced in 2011 to pay for drugs that have not been approved by the National Institute for Health and Care Excellence (NICE) with a budget of £200 million. By April 2015 this budget had increased to £340 million – an increase of 70%.

4. Uterine cancer

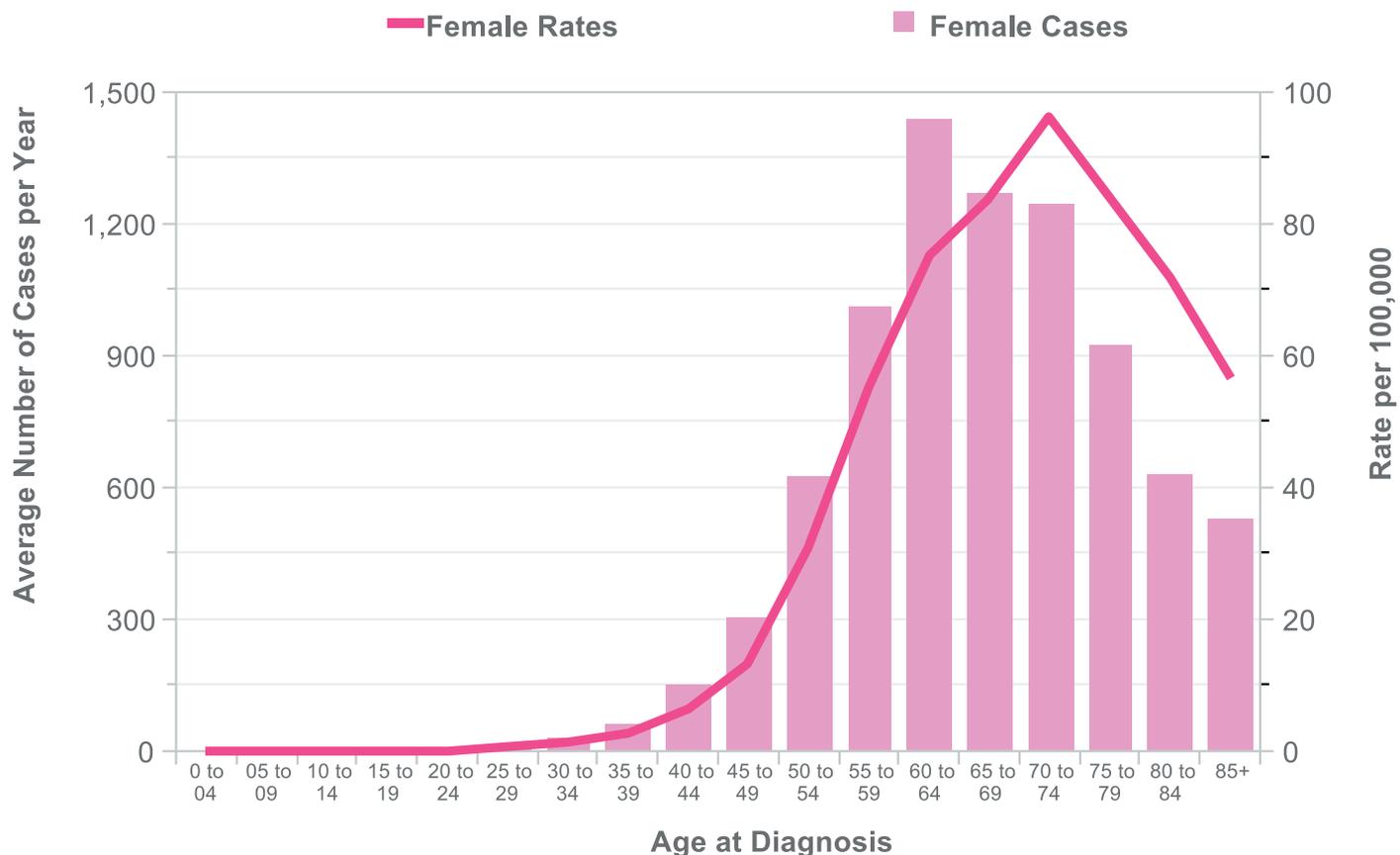
Uterine cancer is the fourth most common cancer in women with 6,946 women in England diagnosed in 2012 and 1,761 deaths in 2013.¹⁰ Incidence increases with age peaking in women aged 70–74; however, each year over 2,000 women over 75 will be diagnosed. It is predicted that the number of new diagnoses in the UK will rise to around 11,000 in 2030.⁴³

The majority of uterine cancers (>70%) are grade 1/2 endometrioid cancers (type 1 tumours) associated with obesity and oestrogen excess, and most of these patients present early with post-menopausal bleeding and should undergo curative surgery +/- radiotherapy.^{45, 46} Obesity not only influences the technical aspects of surgery and anaesthesia, but also the survival of obese patients with uterine cancer which appears inferior to non-obese patients.⁴⁷ Reducing the incidence of obesity is arguably the most important public health problem of this generation, and there is evidence that obesity will overtake tobacco as the leading preventable cause of cancer.⁴⁸ Tackling this is outside the remit of this chapter. However, reducing the incidence of obesity in women will reduce both the incidence of uterine cancer and mortality rates for uterine cancer. Type 1 cancers tend to present at an early stage and if they receive surgery (+/- radiotherapy) generally have a good prognosis. Type 2 uterine cancers, such as grade 3 endometrioid adenocarcinomas, serous, clear cell carcinomas and carcinosarcomas, are more aggressive tumours and are not related to obesity. These patients are usually older and often require chemotherapy in addition to surgery, and have a worse prognosis than type 1 uterine cancers.

Table 11.2 Types of endometrial cancers⁴⁴

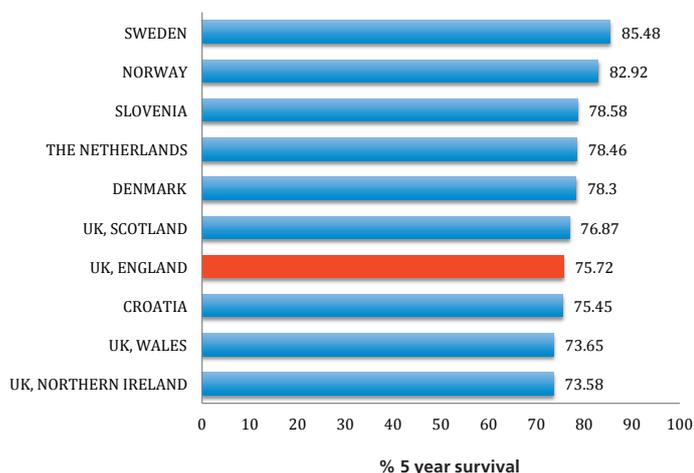
	Type 1	Type 2
Proportion	80–90%	20%
Histology	Grade 1/2 endometrioid	Grade 3 endometrioid, serous, clear cell, mucinous, squamous, transitional cell, mesonephric and undifferentiated
Risk factors	Obesity, endometrial hyperplasia, anovulatory cycles, oestrogen-replacement therapy, oestrogen-secreting tumours	Older age, non-white race, lower BMI, and history of additional primary cancers
Median age	63	67
Proportion early stage (stage I)	70%	50%
Prognosis	Good	Poor

Figure 11.12 Uterine cancer incidence, UK



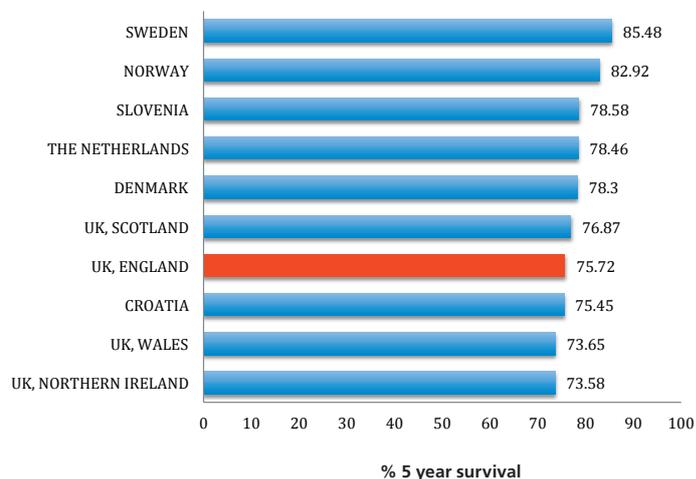
Source Cancer Research UK

Figure 11.13 Uterine cancer five year survival (De Angelis et al. 2013)



Source De Angelis et al. 2013

Figure 11.14 Uterine cancer survival and age



Source De Angelis et al. 2013

Survival

UK uterine cancer survival is lower than other comparable countries such as Sweden, Norway and Denmark. This inferior survival is greatest for older patients. For example, women aged over 75 with uterine cancer have around a 15% lower five year survival rate in England compared with Norway or Sweden.²

The major challenges in reducing mortality from uterine cancer are therefore: 1) addressing the role of obesity on incidence; 2) improving early diagnosis; and 3) addressing the influence of obesity, age and co-morbidity on optimal treatment delivery. Cancer doctors are well placed to support other health professionals in the ongoing management of the co-morbidity of many uterine cancer patients.

Improving early diagnosis

Post-menopausal bleeding is a cardinal symptom of uterine cancer and all patients with this symptom who are not on hormone replacement therapy should receive an urgent referral. Despite the clear symptomatology, 47% of patients ultimately diagnosed with uterine cancer do not promptly present (≤ 14 days) to their GP compared with 26%, 30% and 36% for bladder, renal and breast cancer.⁴⁹

Two studies examining referral rates for 15,614 patients with post-menopausal bleeding reported an overall referral rate of 47.6%. Referral rates were significantly lower with increasing age and co-morbidity.^{50, 51}

Referral rates are low for patients with classic symptoms of uterine (and cervical) cancer, and the lowest rates of referral are in the groups of patients most at risk of poor survival – older patients and those with co-morbidity.⁵²

Recommendation

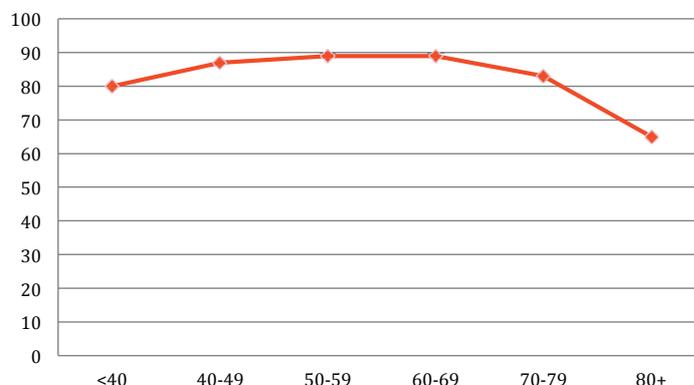
All patients with post-menopausal bleeding should be referred for investigation. Therefore awareness campaigns aimed at the public and general practitioners are needed to increase symptom awareness in older people and those with co-morbidity – in particular the obese.

Obesity and treatment

The cornerstone of the management of uterine cancer is a total hysterectomy and bilateral salpingo-oophorectomy +/- lymph node dissection. Laparoscopic and, more recently, robotically assisted techniques are associated with lower levels of post-operative complications and decreased length of hospital stay, and potentially allow more patients to receive therapeutic surgery where age, obesity or co-morbidity do not permit a safe laparotomy.^{53, 54, 55, 56, 57, 58}

In England surgery rates for uterine cancer are lowest in patients over 70 and in particular for those over 80 where only 65% of patients undergo surgery compared with 89% for those aged 50 to 59.²⁷

Figure 11.15 Surgery rates for uterine cancer by age, England 2006–10



The proportion of patients with uterine cancer receiving minimally invasive surgery has increased from 2.3% in 2001 to 27.6% in 2010.⁵⁹

It is difficult to define the ideal rate of minimally invasive surgery for patients with uterine cancer as not all patients will be suitable – for example, those with a large fibroid uterus, significant pelvic adhesions or cardio-pulmonary co-morbidity limiting Trendelenburg position and pneumoperitoneum. In centres that have adopted minimally invasive techniques, rates in excess of 90% have been achieved.⁶⁰

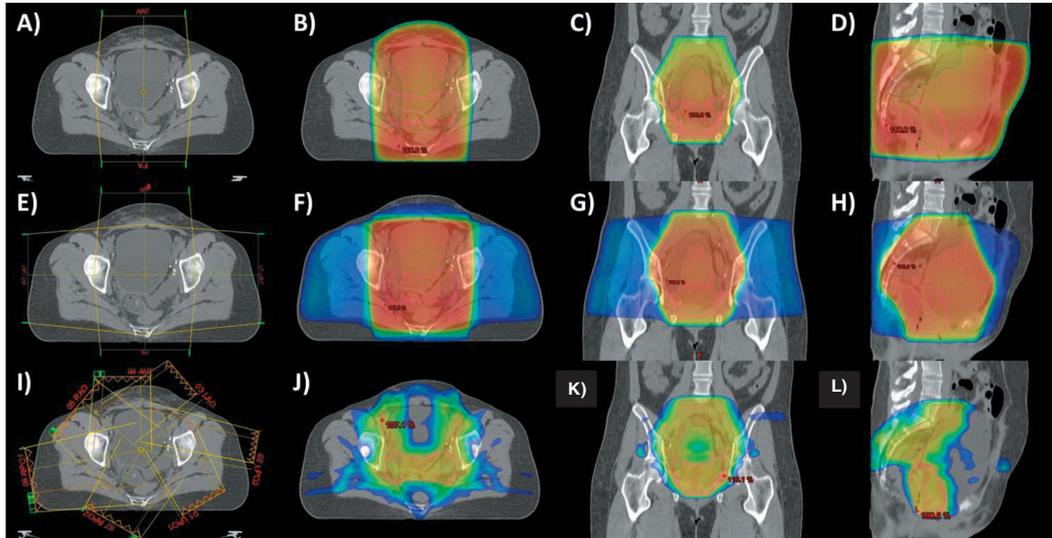
Robotically assisted surgery (RAS) allows more complex surgery to be performed by minimally invasive techniques and also has a shorter training curve than 'straight-stick' laparoscopy. RAS has been a driver for more minimally invasive surgery to be performed, particularly in morbidly obese patients. Although the initial costs of a robot platform are high, its introduction can be associated with lower laparotomy rates and cost savings, increased minimally invasive surgery rates from 17% to 98% within 2 years of the introduction of robotic programme with reduced hospital costs, increased numbers of high BMI patients receiving surgery, and improved short-term outcomes.⁶⁰

Radiotherapy

In patients who are either not suitable for surgery or have risk factors for recurrence, more precise radiotherapy treatment – Intensity Modulated Radiotherapy (IMRT) and Image Guided Radiotherapy (IGRT) – reduces radiotherapy damage to

surrounding tissues and organs and has fewer side effects. There is significant variation in the delivery of IMRT and IGRT in England and there is now continuous audit of national variation and variation by age in order to increase IMRT usage.⁶

Figure 11.16 Tissue sparing with IMRT



A to D: two-field AP-PA technique

E to H: four-field (AP-PA and opposed laterals)

I to L: seven-field IMRT technique

Dosage according to colour wash coding: blue = 50% to red = global max above 100%

Source Hymel, Jones and Simone (2015)

5. Authors' suggestions for policy to address uterine cancer

- Address the obesity epidemic.
- Increase public and primary care awareness and early referral for patients with post-menopausal bleeding and abnormal vaginal bleeding.
- Research the factors leading to patients, particularly older people, not receiving surgery.
- Ensure that all patients have access to centres that can offer minimally invasive surgery – particularly for patients with high BMI or co-morbidity and older people.
- Ensure patients who require radiotherapy have access to IMRT and IGRT.
- Audit incidence and survival trends to allow benchmarking and identification of women most at risk of poor outcomes.

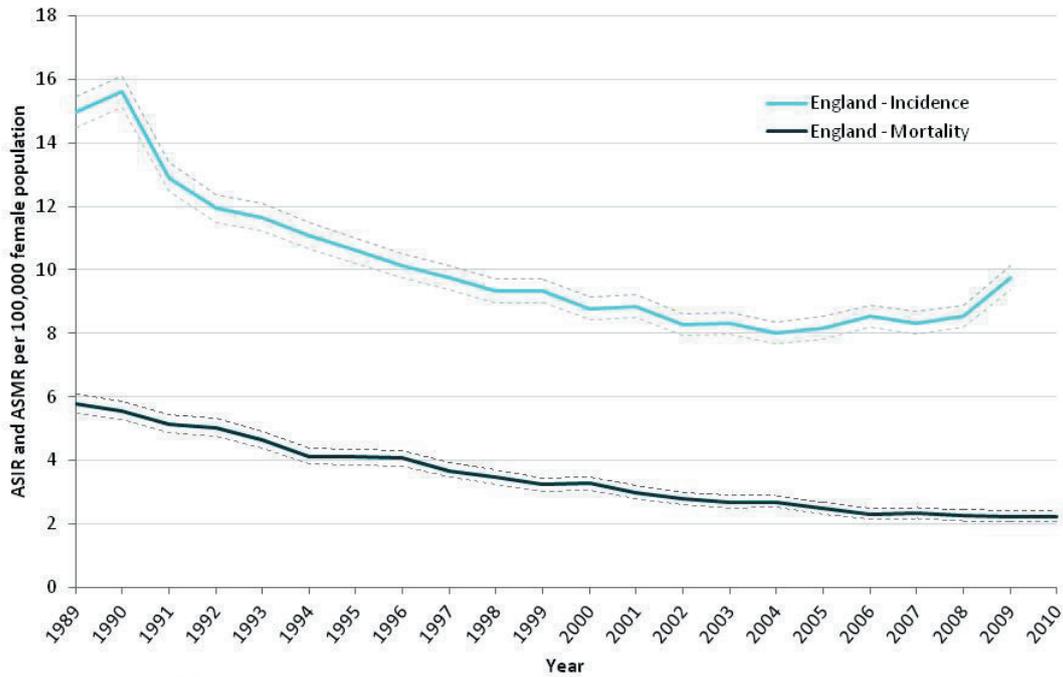
6. Cervical cancer

The reduction in cervical cancer mortality in England is a major triumph of the national screening programme, and the introduction of the HPV vaccination programme is expected to reduce the incidence and mortality further.⁶²

It is assumed that cervical cancer is a problem solved. However, there is a minority of women who are still in harm's way for this condition. These women are outside the screening programme because of their age (<25 or >64 years), or for some reason do not attend or fail to receive an invitation for screening or vaccination. It is therefore important that efforts are maintained and improved to ensure maximal uptake of cervical cancer screening and vaccination. Those women outside the age group for national screening who have symptoms of cervical cancer such as post-coital, inter-menstrual or post-menopausal bleeding must be adequately assessed and referred, which is a problem in primary care.^{52, 63} Some young women who have not been screened can still be cured of their cervical cancer but are diagnosed too late to be offered fertility-preserving surgery. This is in part a consequence of the change in age of first screen from 20 to 25.⁶⁴

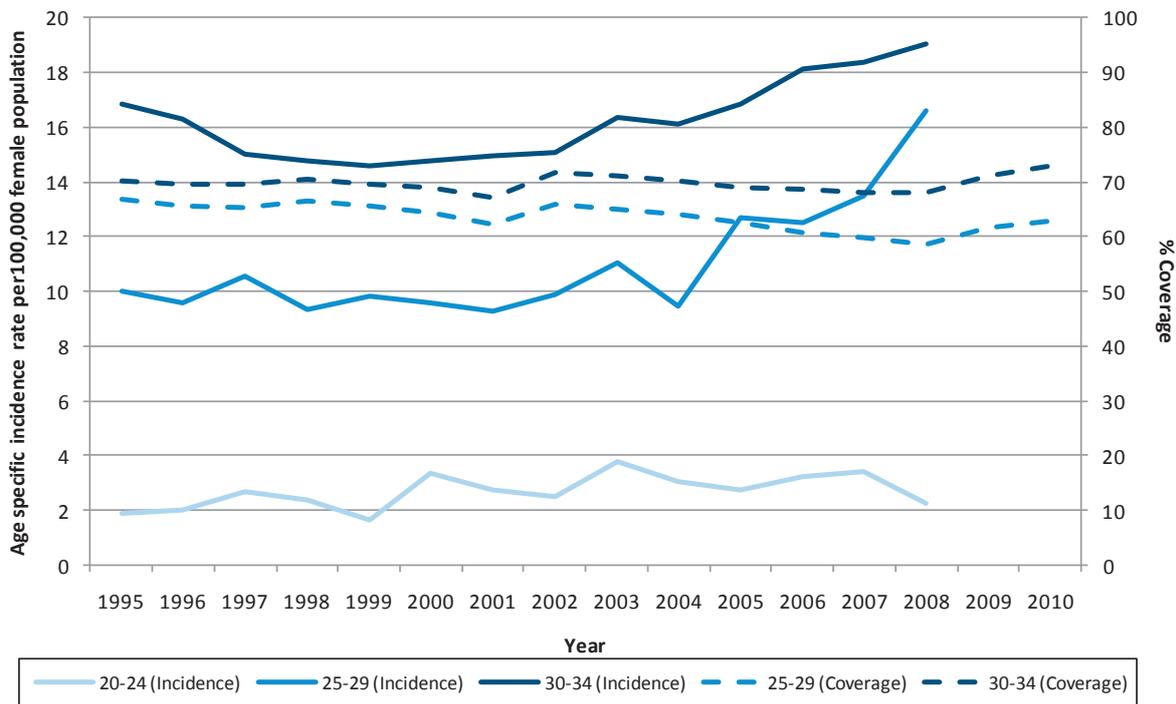
Another group of women for whom the cervical screening and vaccination programmes fail are those in detention centres, refugees, asylum-seekers, prisoners, homeless women and travellers. These women are in harm's way.⁶⁵

Figure 11.17 Trends in cervical cancer incidence and mortality in women under 40, England 1989–2009



Source UK Cancer Information Service and HSCIC (2010)

Figure 11.18 Recent trend in cervical cancer incidence, ages 20–34 (1995–2008) and coverage of screening ages 25–34 (1995–2010*), in England



7. Conclusions

There has been steady progress in outcomes for women's cancers in England but most other high income countries are still doing better. There remains a particular issue with ovarian cancer and older patients with any cancer. Focusing our efforts in three areas would go some way to reversing our continuing relatively poor survival.

8. Authors' suggestions for policy

1. Diagnostic pathways

Fewer than half of all cancer patients are referred via two-week referrals and expediting cancer diagnosis solely through this route is unlikely to be effective, particularly for ovarian cancer. The introduction of diagnostic pathways and diagnostic centres for the investigation and assessment of non-specific but potentially serious symptoms could have a significant impact on outcomes.

2. Cancer treatment

Treatment inequalities should be addressed including under-treatment in older people and those with co-morbidities, minimally invasive surgery for uterine cancer, clinical trial activity, new drug usage, and perhaps most importantly capacity and appetite for complex ovarian cancer surgery in order to improve the rates of complete cytoreduction.

3. Cancer information and audit

There should be continued investment in cancer intelligence to allow a widening of its scope to include more detailed analysis of pathways and interventions in relation to outcomes, for example interrogation of the Systemic Anti-Cancer Therapy Dataset and Hospital Episode Statistics datasets. There is a specific need to address the low survival of ovarian cancer patients by annual national audit.

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Chapter 12

A human rights approach to women's health

Chapter lead

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1. Overview

Women's health raises issues of human rights and these have been increasingly recognised in recent decades. However, there remain inequities which different societies are addressing with varying success. In this chapter, we examine how the increasing interest in human rights and women's health has come about, as well as discuss what its implications may be for women's health going forward. We review the applicable human rights and consider the duty of the state and its agents. But human rights do not themselves sustain a human body; our subject is the protection afforded by those rights to women's health. If a woman is experiencing domestic violence the failure of a state agency responsible for her protection gives her legal recourse but does not change the harm she has experienced, so the legal position does not dispose of the human issues that are stake.

2. Development of human rights

The rights of the individual have been debated as far back as we have knowledge. Many of the fundamental rights were identified by Greek and Roman philosophers and their debates have continued ever since. The pragmatism of the 18th century was encapsulated by Englishmen living in America, when they held certain rights to be self-evident.¹ However the debate since then has suggested that they were optimistic in the appeal to simplicity inherent in their Declaration of Independence.

After the Second World War, the world made a determined effort to lay legal foundations that would control nation-states and prevent a recurrence of fascism. The result in 1948 was the Universal Declaration of Human Rights (UDHR),² courtesy of the newly formed United Nations (UN). In Europe, the European Convention on Human Rights (ECHR, 1953) followed shortly after,³ which was signed by the UK following which cases could be taken against the UK government to the European Court of Human Rights for adjudication. This was not passed into UK law until 50 years later as the Human Rights Act 1998 (HRA) and now is directly enforceable in UK courts.⁴

Because the focus was on the desire to control oppression by the state, many of the rights were framed in negative terms: freedom from being killed, tortured or placed under arbitrary arrest. They were enforceable only against the state by courts, often international courts. As a result, the enforcement still depends upon identifying what the lawyers call an 'emanation of the state' that is infringing the right. However, the secular context in which these legal frameworks operate has changed beyond all recognition and therefore there is much debate as to what the interpretation of rights should include and whether the existing framework is fully able, is often not able to protect the human rights that are vital to the woman of today.

The same post-war optimism also made 1948 an important year in UK medical history, with the advent of the NHS. However, health was marginalised from international politics: the statesmen who built the new order knew that health was important, but they did not think it was mainstream business for the UN, which was concerned with realpolitik. Thus the UDHR contains only passing reference to medical care, and the right to the highest attainable standard of health was delegated to a subsidiary agency, the World Health Organization (WHO), the constitution of which defined health as: 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (1946).

This definition includes the crucial recognition that health is an intangible entity dependent on the stable organisation of society and various services, of which medical care is by no means the sole or even the most important factor.

However, the late 1940s were also when antibiotics first promised to put doctors in charge of the infections that had plagued humanity throughout its history; it may be seen as the time when modern medicine emerged to become what Roy Porter called 'the greatest benefit to mankind'.⁵

Since then we have seen the burgeoning of modern medicine, in which humanity has achieved an unprecedented ability to control disease and deliver good health where there is an effective service, alongside advances in sanitation and more efficient food production and storage. That ability has created challenges that no system has yet resolved satisfactorily, as increasing longevity and the burden of disease from changing lifestyles has proved to be unexpectedly expensive in England. However, the process has sought to put the needs and dignity of people at the heart of healthcare planning, although recent scandals in Mid Staffordshire and Morecambe Bay question whether this is being universally realised.

As a result, health issues have become increasingly important human rights experts and others who have belatedly recognised that effective medicine plays a crucial part in delivering 'the good life' that we all aspire to and increasingly see as our right. Even those insisting on a broader view in which we confront inequality and unfairness also recognise that access to high-quality healthcare is an important part of the good life.⁶

For any right to be legally enforceable, there must be some corresponding duty on another person or organisation against whom the right can be enforced. Many of the needs of women are being denied in circumstances where there is no emanation of the state that can be identified as responsible for the infringement, and we need a much broader coalition to meet the challenge.

A human rights approach can also involve a power analysis and an analysis of the structural impediments to fulfilment of human rights, which is beyond the scope of this chapter. Models such as the Hagemann-White model for violence against women (described in the Gender-Based Violence chapter of this report) illustrate this approach.⁷ If rights are to be delivered, it could be argued that this duty cannot be confined to the state. At different times, those with moral and legal responsibilities the individual themselves, their family (when they are children, infirm or vulnerable to domestic violence), their social network, their educators, their employers, their local and national governments, and their health and social care services. The breadth of the determinants of health means that potentially any service provider, infrastructure network, retail organisation and those influencing social trends could be deemed to have an ability to impact upon the health of an individual of whom they often have no knowledge. Plainly this may lay the moral and ethical obligation for delivery of human rights too wide for practical enforcement by the law, but the state should acknowledge a duty to improve the legal and regulatory environment that will influence how these obligations will be viewed by others.

The universal human rights as defined by the UHDR can be seen to contain certain things that we now see as elements or determinants of health. These include a number of positive rights to various things, including:

- a standard of living adequate for health and wellbeing
- access to medical care
- benefit from scientific advancements.

There are alternative lists that can be used, such as the 12 reproductive rights (see boxed text).

Box 12.1 Reproductive rights are human rights

1. The right to life
2. The right to liberty and security of person
3. The right to health, including sexual and reproductive health
4. The right to decide the number and spacing of children
5. The right to consent to marriage and to equality in marriage
6. The right to privacy
7. The right to equality and non-discrimination
8. The right to be free from practices that harm women and girls
9. The right to not be subjected to torture or other cruel, inhuman or degrading treatment or punishment
10. The right to be free from sexual and gender-based violence
11. The right to access sexual and reproductive health, education and family planning information
12. The right to enjoy the benefits of scientific progress

From Centre for Reproductive Rights, see <http://www.reproductiverights.org/>

The essential point is that all people are entitled to these rights without distinction of any kind, including by sex, age or race,^{2, 3, 4} but the safeguarding of those rights demands a recognition of the ways in which different groups are threatened. This requires an understanding of their needs and the ways in which their rights are challenged. This understanding is part of the platform of equality and equity that should be accepted by modern society.

An acceptance of the ethical principle of equity lies at the heart of a rights-based approach to health. However, economic and social considerations are also inextricably involved. *Fair Society, Healthy Lives* recommended a fairer distribution of health and a reduction of health inequalities and pointed out that these were a means of increasing productivity and tax revenues and of reducing welfare payments and treatment costs.⁸ This repeated arguments advanced by the original architects of the NHS, who argued that health contributes to the 'asset value' of a person because injury or illness may impair a person's ability to work. Conventional wisdom accepts that the wealth of society can be increased through investments in health and nutrition.⁹ More mundanely, the cost of morbidity is a burden on the whole of society, even though it often falls unevenly.

Socially, a human rights-based approach offers a mechanism for the enactment of the aspiration upon which the NHS was founded – that is, a collective principle of social justice. Thus the promotion of health does combine an asset-based approach and a human rights-based approach.

The human rights of women have been highlighted through international collaborations, such as the Convention for the Elimination of Discrimination Against Women (CEDAW)¹⁰ and the 1995 UN Beijing Platform for Action, where Hillary Clinton declared that 'Human rights are women's rights and women's rights are human rights, once and for all'.¹¹ These conventions have led to a recognition of the need to confront the exploitation of women in trafficking and sex work, as well as the denial of education and the need to promote equal access to medical care and family planning, equal remuneration for work and the right to decide freely on the number and spacing of children, as extensions of the universal human rights.

The ways in which these rights are infringed varies in different societies. War, poverty and the absence of the rule of law all create extreme circumstances that have less impact in England than other places. However, other gender-specific human rights issues identified from the HRA and CEDAW in this chapter are evident in the UK and are relevant to this year's Chief Medical Officer (CMO) annual report.

3. Right to life

This is the most fundamental of all human rights and its protection is the core obligation that is imposed on the state. The improvement in longevity over the last 60 years shows what can be achieved when society is well organised, but the inequalities that continue are evidence that this improvement is a work in progress. The Lives on the Line tube map shown in Figure 12.1 below,¹² which shows a 20-year variation in life expectancy at birth among people born in different parts of the same city, illustrates the extent to which our society is failing to secure an equal entitlement to this fundamental right.

How far the right to life raises issues for women's health depends on the context. There are data that can be interpreted as showing both men and women at a disadvantage. Women live longer but the gap is narrowing due to a faster increase in life expectancy for men (see Figure 12.2).

Access to the right to life is pertinent to pregnancy and abortion. Life is legally determined to begin at the moment of birth, marked by a transition from reliance on the mother and placenta for oxygen and nutrition to exogenous supply. Human rights are applied to a neonate but not a fetus.

In pregnancy, the right to life applies only to the mother in UK law, although destruction of a fetus outside of the terms of the Abortion Act 1967 is a criminal offence.¹³ In English clinical practice, a mother's survival and quality of life is placed ahead of that of the fetus. A termination of pregnancy or abortion may be carried out under clauses of the Abortion Act. Legalised abortion reduces morbidity and mortality from illegal abortion and so has a role in improving women's health.¹⁴

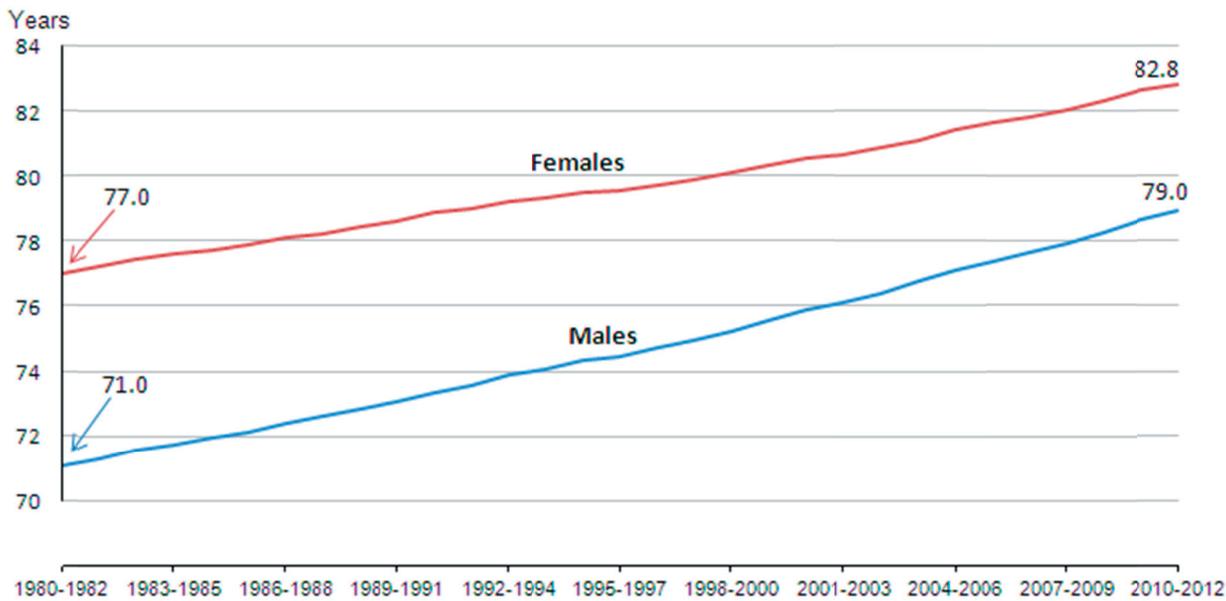
The European Court of Human Rights has recognised that there are widely different attitudes between countries such as Italy, Spain and Ireland (that do not permit abortion) and those such as England, Germany and the Scandinavian countries (that take a more liberal view). The court has accepted that European law permits a 'margin of appreciation', which means in practice that it will not criticise practices that reflect the laws in individual countries. At the same time, it will entertain complaints that the practice in individual countries does not respect the rights of women according to the law that has been enacted. So that where abortion is legal in Poland, for example, the court was prepared to criticise a failure to afford access to pre-natal screening that would enable a woman to decide whether to exercise her right.

Figure 12.1 Lives on the Line: Life expectancy at birth and child poverty as a Tube map (2012)



Source Cheshire, J. 2012. Lives on the Line: Mapping Life Expectancy Along the London Tube Network.

Figure 12.2 Life Expectancy at Birth, England and Wales, 1980-1982 to 2010-2012



Source Office for National Statistics

4. Liberty and Security and Freedom from torture, cruel, inhuman or degrading treatment or punishment

Box 12.2 Components of the Index of Multiple Deprivation

- Income
- Employment
- Health deprivation and disability
- Education, skills and training
- Barriers to housing and services
- Crime
- Living environment

<http://data.gov.uk/dataset/index-of-multiple-deprivation>

The second fundamental human right guaranteed by the ECHR raises many gender issues. Violence against women including forced marriages, female genital mutilation, trafficking and cruel and degrading treatment in care homes reduce women's ability to participate in society as well as affecting their mental and physical health (see Chapter 2 of this report, 'Gender-based violence against women'). Women experience higher annual and lifetime prevalence of domestic violence than men.

The *National Survey on Sexual Attitudes and Lifestyles* reported that one in five women and one in 20 men in Britain report experiencing attempted non-volitional sex,¹⁵ and one in 10 women and one in 71 men report experiencing completed non-volitional sex since age 13.¹⁶ As well as gender inequality in the rates of sexual violence, there is a significant social gradient in this violence for women but not for men,¹⁵ and this inequality has mental and physical health impacts.¹⁷

There are also numerous cultural issues that are more onerous for women in various minority groups. These include arranged/forced marriages and 'honour-based' violence, trafficking, female genital mutilation and other forms of domestic violence.

Because women live longer than men, they outnumber men in older age groups¹⁸ and there are 2.8 women for every man over the age of 65 in care homes, although this ratio is reducing.¹⁹ A human rights prism helps to illustrate the nature of the cruel and degrading treatment found in some homes, which it can be expected will affect women to a greater extent than men. Whether the ECHR imposes an obligation on the state depends upon the precise legal structure of the institution, including the way it is organised, regulated and financed. Whether the state has assumed responsibility for the care of the residents actually depends upon subtle distinctions.

5. Access to a standard of living adequate for health

The links between lower pay and poor nutrition and obesity mean that poverty is a determinant of multiple deprivation (see Box 12.2).¹⁷ Levels of obesity in England are similar for men and women, however amongst adults with lower educational attainment obesity is higher in women and the same picture is seen in ethnic minorities (ref. NOO).

The gender pay gap is higher in the UK than the Organisation for Economic Co-operation and Development average.²⁰

The gender pay gap in full time workers is 9.4% and for all employees was 19.1%.²¹ The gender pay gap in full time workers appears to be higher in the private sector than in the public sector. Beyond measures that public sector employers may take to reduce the pay gap, this suggests that further legislation to create an environment for employment equity is needed to address women's rights to equal pay and access to an adequate standard of living.

6. Access to healthcare

The National Health Service is free at the point of delivery but access should be considered more widely so as to capture the availability of suitable services at a personal cost which is acceptable to the user.²² English women rarely face the same barriers as women in low-income countries but there are sometimes more subtle access issues which may breach their human rights.

7. Benefit from scientific advances

Access to healthcare may also be assessed by the standard of care offered and the extent to which it is based on validated evidence. Other chapters in this report present multiple examples of the health system's failures to follow such guidance and the associated morbidity and mortality, such as a failure to diagnose gestational diabetes.

One CEDAW principle highlights the number and spacing of children as a right for women. In a 2012 report, up to 3.2 million women between the ages of 15 and 44 were found to be living in areas where fully contraceptive services were not available; these areas had abortion rates higher than the national average.²³

8. Conclusions

The human rights of women in England are protected by the law insofar as they can identify an emanation of the state that is infringing them. The law is blind to other parties' infringements of human rights. Many of the things that really matter to women, such as the right to health and to protection from domestic violence, are vital human rights – as is the right not to be impregnated at a time not of their choice.

Women in England live longer than men, but with a greater proportion of their lives affected by disability, and have shorter life expectancies than women in some other EU countries, eg Greece, Slovenia and Portugal. Women as a group are paid less than men and experience specific human rights disadvantages evidenced by increased rates of rape, domestic violence, 'honour-based' violence and trafficking compared with men. Women access healthcare more often than men but may be denied access to basic services such as contraception. Considering the human rights applicable to women's health may have relevance to the planning of medical services and provides an approach that promotes equity.

A human rights approach can help to draw health issues experienced by women together and highlight areas where disadvantage is gendered.

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Devising recommendations

To create my report, I began with a 'Scoping Workshop' which brought together experts in different areas of women's health. This helped to set the parameters for the report and ensure that I did not duplicate other reports or major works currently in production. After I read the chapters submitted by Chapter Leads, I created a summary and synthesised draft recommendations from this information; these draft recommendations were then discussed at a 'Recommendations Workshop'. My Editor-in-Chief continued to discuss and refine draft recommendations until I finalised my recommendations. This is a lengthy process which draws upon the knowledge and assistance of many people. I thank all of the following for the part they played in helping to inform my recommendations.

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