

Inclusive Practice

Vulnerable Migrants, Gypsies and Travellers, People Who Are Homeless, and Sex Workers: A Review and Synthesis of Interventions/Service Models that Improve Access to Primary Care & Reduce Risk of Avoidable Admission to Hospital

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Foreword

"It is more important to focus on the systems which trigger and cause vulnerability and aim to correct those rather than the people who were adversely affected. Vulnerability isn't a characteristic of disadvantaged people but of the "social spaces" they have to occupy in unequal societies."

<u>Source</u>: Understanding vulnerability. Workshop of the Data and Research Working Group, Inclusion Health Programme, May 2012

Our report "*Inclusive Practice*" is founded on this definition of vulnerability. Instead of seeking to focus on the characteristics of individuals, we have attempted to provide a foundation for understanding the changes that might need to be brought about in the health and related systems to meet the needs of individuals living in an unequal society.

Inclusive practice was commissioned and overseen by the Data and Research Working Group of the Inclusion Health Programme and approved for publication by the National Inclusion Health Board. It is one of a series of reports from the Inclusion Health programme.

Inclusive Practice provides a detailed synthesis of the scientific literature within the UK and elsewhere, of the impact of efforts to provide good access to primary care and to prevent avoidable hospitalisation for the four vulnerable groups identified in the Department of Health Inclusion Health programme: vulnerable migrants, Gypsies and Irish Travellers, people who are homeless, and sex workers.

The challenges of providing accessible primary care are manifold at a time of economic constraint, especially as this report shows that improving registration rates for vulnerable groups is only the first step in providing a truly accessible service. The paucity of independent evaluation of models of primary care speaks volumes about the value we attach to some of the most disadvantaged groups in society, as does the myriad of start/stop projects we reviewed whose future funding was uncertain.

Despite this, there are many examples of promising practice that are waiting to be more widely adopted. We hope this report will provide a stimulus to reducing the widespread variation in access we have identified and to further research into the unanswered questions we have identified.

Dr Bobbie Jacobson OBE, Chair, Data and Research Working Group,

Inclusion Health Programme.

February 2014

Inclusive Practice

Executive Summary and recommendations

A review and synthesis of the evidence on improving access to primary care and preventing avoidable admission to hospital among vulnerable migrants, Gypsies and Travellers, people who are homeless, and sex workers.

1. Introduction and Background

This report forms part of the work led by the Department of Health's National Inclusion Health Board. It is the second in a series of reviews commissioned by the Data and Research Working Group of the Board. The membership of the working group is attached at Appendix 2. The Board's focus so far has been on four vulnerable groups whose health experience has been particularly poor:

- Vulnerable migrants, notably, refugees and asylum seekers
- Gypsies and Travellers
- Homeless people
- Sex workers

Its first report "Hidden needs" reviewed the availability and gaps in routine data and surveys covering the needs and health outcomes of these four groups. It identified significant gaps in the definition, collection, reporting and analyses of these groups. It made a number of recommendations including working with research organisations to develop and commission specialist surveys to bridge the gap in good use/outcomes data in vulnerable groups.

This report follows on from this work with the aim of: reviewing the literature on improving access to primary care and prevention of avoidable admissions to hospital for the four groups.

2. Definitions

2.1 Vulnerable Migrants

Asylum seekers (including failed asylum seekers), refugees, and undocumented or irregular migrants (including those who have entered the country illegally and migrants with irregular documentation, such as visa overstayers) are included in the definition of vulnerable migrants. Other groups may be vulnerable with respect to health care access (e.g. students from overseas).

2.2 Gypsies and Travellers

This report uses the term 'Gypsy or Irish Traveller', as defined in the 2011 England and Wales Census. However, the term as used in this report also encompasses Roma people.

2.3 People who are homeless

The vulnerable segment of this population is defined by the Department of Health and in this report as people who are rough sleepers or those sleeping in a hostel, a squat or on friends' floors (insecure or short-term accommodation). These groups frequently cycle in and out of street homelessness. The definition does not include people such as families (with children) living in temporary accommodation provided by a local authority under homelessness legislation. The definition also excludes people living in overcrowded or unsuitable accommodation. However, it is acknowledged that persons who fall into these other categories of homelessness may also experience vulnerability. They are excluded by the Department of Health because '... although their housing may be unsettled (potentially leading to increased health problems as a consequence), they are not considered to have substantially different health needs to the mainstream population, and will not generally have significant problems in accessing primary health care'.

2.4 Sex workers

This term encompasses those men, women, and transgender persons working on the streets, and in such settings as massage parlours, flats, and as part of an escort service, to the exclusion of the wider sex industry, where the motive for sex is money. Throughout this report the term 'sex worker' has been used in contradistinction to 'prostitute' which has derogatory connotations. The choice of terms in the policy literature varies. While bodies such as the Department of Health and National Inclusion Health Board use 'sex worker', the salient term in Home Office publications is 'prostitute'.

3. Methods

3.1 Search Strategies

An initial scoping study was undertaken in December 2012 which showed the literature to be limited and heterogeneous, often located in the segment that is non-peer-reviewed. This was followed for the health and social care peer-reviewed journal literature by highly structured Boolean search algorithms built around a PICO (Population-Intervention-Comparison-Outcome) framework and of hand

searching of key journals. Use was also made in the search strategy of tools such as the Cochrane Guidelines for public health reviews. Very few examples of use of robust evaluative methodologies (RCTs, case-control studies, *et al.*) were located. Nevertheless, for each of the four vulnerable groups, some interventions were found that had been evaluated. The grey literature was comprehensively and systematically searched using grey literature databases and a range of search engines and algorithms for quality web-based literature. This source yielded the majority of studies of interventions, though many were small-scale, descriptive and observational. Further, of the very small number that had been evaluated, such evaluations were primarily descriptive rather than analytical and had been undertaken by teams responsible for the intervention.

Only limited use has been made of the international literature where it is judged relevant. For example, many of the reported studies of interventions for sex workers are in resource poor countries which may have only limited applicability to the UK context. However, a number of good practice examples of *cultural mediators* and *peer educators* have been drawn from mainland European countries.

3.2 Synthesis

For the <u>peer-reviewed literature</u>, the review has been conducted on the basis of the specification of the inclusion / exclusion criteria for studies to be reviewed. Within this, the issue of comparators has been addressed (direct vs indirect comparisons, outreach vs non-outreach interventions, etc.).

The use of quality assessment tools has been judged to have limited appropriateness given the nature of much of the evidence. An attempt has been made to assess the wider applicability of the interventions with respect to relevance, feasibility, sustainability, etc. (including views of community groups and staff in specialist services).

Definitions and descriptions of the interventions are set out in the review with respect to the target population (including which of the four vulnerable groups and, where relevant, the size of the local population receiving the intervention), the scope of the interventions covered, including wider determinants of health, and outcomes measures (intermediate / process outcomes and final outcomes where available).

For the <u>grey literature</u>, the source of most of the interventions, a different but complementary approach known as *realist synthesis* has been applied. This methodology attempts to answer the question: 'What works for whom, in what circumstances, in what respects, and how?'

3.3 Quality grading of evaluations and impact

An attempt has been made to prioritise well-described and documented interventions that have been formally evaluated.

In order to help readers assess the quality of evaluations, a quality grading system has been devised that seeks to take account of the robustness and comprehensiveness of the evaluation, and whether it was independently undertaken or not. The review has identified evaluations of quality which have been undertaken by teams delivering the intervention so independence is not a necessary requirement of robustness or quality. 4 grades are identified:

[G1]: Incorporates some assessment of process (intermediate outcomes), user-assessed final outcomes, and cost evaluation (cost effectiveness or return on investment [ROI] type calculations at best, otherwise costs of providing the service)

[G2]: Incorporates some assessment of process and user-assessed final outcomes but no cost data

[G3]: Incorporates some assessment of process and/or final outcomes (not user-assessed)

[G4]: General descriptive accounts of the intervention or expert opinions, but without an explicit focus on evaluation (process or final outcomes). Although descriptive, a significant proportion of grade 4 interventions have been cited as good practice examples and in some cases have been the recipients of awards for innovative practice *et al*.

IE = independently evaluated; NIE = not independently evaluated (this attribution is not relevant to interventions graded 4)

4. Findings for Vulnerable Migrants

4.1 Policy on access to primary and secondary care

- There is no required minimum period of stay in the UK before a person including asylum seekers, refugees, and failed asylum seekers can be registered with a GP. GPs can only decline such people if their list is closed or on non-discriminatory grounds.
- GPs have a duty to provide emergency treatment free of charge regardless of migrants' residential or registration status.
- Charging regulations in secondary care have frequently changed. Since May 2012 a person granted asylum, temporary or humanitarian protection under immigration rules is exempt from NHS charges and should be recognised as a refugee.
- Those seeking asylum, where the outcome is not known, are also exempt from secondary care charges.
- Failed asylum seekers are generally liable for NHS hospital treatment charges, although there are exemptions for those continuing to be supported by the Border Agency.

- Since October 2012 diagnosis *and treatment* for HIV/AIDS is now free to all overseas visitors.
- On 3 July 2013 a further open consultation was launched on migrant access to the NHS, which includes plans to end free access to primary care for all visitors and tourists.

4.2 Access to Primary Care

- Studies of registration levels for refugees and asylum seekers are variable in quality and often specific to particular parts of the country only. The most robust estimates suggest that only about a third of all generic new entrants to the UK. Within this group asylum seekers were least likely to become registered (around 19%) compared with other migrants. It should be noted this evidence is based on those entering the UK from countries with a high risk of TB who underwent port health tuberculosis screening.
- Surveys focused on major urban centres such as London show much higher registration rates have been achieved, including rates in excess of 90%.
- Significant and continuing barriers to registration continue to be reported including: the unwillingness of practices to register asylum seekers; a shortfall in translation services; lack of knowledge of eligibility by practice staff; and burden of documentation required to show proof of residence.

4.3 Elements of Promising Practice in Primary care

- A number of promising, but largely unevaluated models of service have developed, mostly based within urban centres with large concentrations of refugees/asylum seekers, including London, Sheffield, Nottingham, Sandwell and Glasgow.
- Elements of good practice that have been identified include:
 - The incorporation of health advocates to help navigate barriers to registration can significantly increase registrations
 - The development of specialist GP practices for refugees and asylum seekers
 - In the absence of specialist practices, using contractual arrangements such as Locally Enhanced Schemes to incentivise general practice.
 - New entrant schemes to facilitate registration and assessment, including bussing of new arrivals from Induction Centres to specialist and other practices

4.4 Prevention of Avoidable Hospital Admission

- Few interventions have been identified; it is likely that avoidable attendance at A&E can be prevented by effective registration in primary care, but there are no robust evaluations to demonstrate this.
- For asylum seekers, one of the main issues for concern is whether practitioners can be trusted to interpret eligibility rules for free care correctly.
- Maternity care is a major health issue; some parts of the country have developed maternity care pathways for non-English speaking migrants but barriers to GP registration inhibit cost effective maternity care.

5. Findings: Gypsies and Travellers

5.1 Policies

The government has established a Ministerial Working Group to facilitate improving the life chances of Gypsies and Travellers. This has yet to endorse specific policies to improve access to primary care and has been criticised for not adequately engaging Gypsy / Traveller organisations in its work. Amongst other policy initiatives, the Equality and Human Rights Commission has highlighted, in the context of the Dale Farm evictions, that the right to a home is protected in Article 8 of the European Convention on Human Rights (the right to respect for private and family life, home, and correspondence).

5.2 Access to primary care

- Numerous largely geographically specific studies have reported wide variation in GP registration rates for Gypsies and Travellers, ranging from 80-100% but as low as 40%. The lowest levels were recorded in one study for those living in trailers (38%) and those who travel all year (37%).
- By contrast, in Northern Ireland, registration rates of over 90% have been reported.
- Barriers to registration include: a reluctance to fill in forms, mobile lifestyles, temporary registration status often given, and poor response to written materials due to literacy problems.

5.3 Elements of good practice in primary care

A number of promising services have been identified, in both rural and urban areas. Many initiatives have focused on meeting a range of key health needs of Gypsies / Travellers, including maternity and child healthcare, dental health and health promotion, and generic health awareness projects. Improving GP registration is often seen as one element of these programmes. Examples of models of promising practice include Leeds, Sheffield, Barnsley, Cambridgeshire, South East coast, and Bristol. The Pacesetters Programme, funded by the previous Government, has helped ensure that a number of initiatives have been independently evaluated.

The recurring elements of good practice include:

- Gypsy / Traveller engagement in the design and delivery of the service is central to the success of any model
- Building confidence and trust through a "trusted person" and core services is essential
- o Time and costs of community input should be built into budgets
- The development of hand-held records is seen as good practice, but not all the evidence supports its implementation
- A GP enhanced service model has been drawn up with detailed specifications

5.4 Elements of Good Practice in Secondary Care

There were few studies identifiable for this group. The lack of adoption of the 2011 Census ethnic category for Gypsies and Travellers in hospital episode statistics (HES) makes this task harder.

6. Findings: People who are Homeless

6.1 Policy

The Cross-government Ministerial group on Preventing and Tackling Homelessness has focused on reducing the risks of homelessness in groups such as single men and women who are outside the legislation on homelessness. It has also focused on reducing street homelessness by supporting efforts to prevent people from being discharged from hospital on to the street and to ensure that housing benefit changes do not have an adverse impact. A number of coordinated, resourced voluntary sector initiatives have reduced rough sleeping. The Localism Act has allowed local authorities more flexibility in offering rented private sector accommodation if it meets a "suitability" threshold.

6.2 Access to Primary Care and Prevention of Avoidable Hospital Admissions

As there is still no common agreed definition of homelessness across government, studies of GP registration rates may not be comparable. The most reliable audits by Homeless Link have found a registration rate of 82-85%, most with permanent registration. Registration rates with dentists are much lower at around 40%.

For most single homeless people barriers to registration and receipt of effective primary care relate to their chaotic lifestyles, often worsened by drug and alcohol misuse. In addition the mobility of homeless people makes it difficult to engage with the rigid opening hours of core services. This often results in a pattern of deferring consultation until health issues become acute and can lead to frequent attendance in hospital, the so-called "revolving door" phenomenon.

6.3 Elements of Good Practice: Primary and Secondary Care

Numerous models of care have been developed, ranging from: no specialist/mainstream provision through to nurse-led outreach to a fully dedicated, specialist homeless service integrating both primary and secondary care. The fully integrated model includes an intermediate "step-down" facility that is currently being piloted in London and will be evaluated. There are also a number of mobile clinics that provide services to homeless people and others such as sex workers. Surveys indicate that about one third of former Primary Care Trusts do not provide any specialist homeless services, a quarter provide outreach, and 10% provide temporary registration. This finding does not in itself define good practice as cost-effective practice models will be related to the size of population served.

Most of the models across the range have not been evaluated. Notable exceptions are the city- wide Integrated Services for Homeless People in Boston, USA and the London Healthcare Pathway for Homeless People in London. The Boston service is a mix of primary, outreach, intermediate and hospital care: its notable achievements include medical respite care that bridges the widening gap between hospitals and shelters, an electronic medical record system that coordinates care and monitors quality measures across two hospitals and 80-plus shelter and street clinics, multidisciplinary teams that integrate medical and behavioural care and ensure continuity of care, the inclusion of the homeless in the programme's governance and design of services, and consistent provision of preventive services. The London Healthcare Pathway involves a fully funded discharge planning team with primary care leadership, hostel involvement, and a health care navigator with experience of homelessness. This is one of the very few evaluations identified in the review that has demonstrated both a reduction in use of in-patient care and an increase in cost-effectiveness. It is now being adopted by several other trusts serving urban populations.

There are a number of intermediate care services based within or separately from homeless hostels. The need is based on the assumption that many homeless people have chronic conditions that require continuing care and rehabilitation that does not require the full services of an acute hospital. The largest, led by St Mungo's in London, has shown promising results in relation to improved health of its clients, better engagement with services, and significantly reduced use of hospital care.

Key emerging elements of good practice include:

- Multidisciplinary care across sectors
- Person-centred care
- Service user engagement and influence
- Inclusion of linked primary, hospital and respite services
- o Coordinated care and effective discharge planning in hospital
- Specialist services/facilities in areas serving high concentrations of homeless people

7. Findings: Sex workers

7.1 National Policy

The Department of Health's sexual health framework acknowledges the need to provide specialist services to meet the significantly poorer health experience of sex workers and to address the sensitivities of sex workers to disclosure in statutory services. Both the Department of Health and the Home Office have supported initiatives to protect sex workers from violence, to prevent and arrest sex traffickers, and to facilitate the better reporting of violence to the police. Some of these initiatives have had a positive effect although a recent policy change before the Olympics that resulted in the closure of a number of brothels in the Olympic boroughs resulted in a serious fall-off in attendance of sex workers at well-established specialist sexual health clinics.

7.2 Access to primary Care

GP registration rates, mainly in major urban areas, have been reported at about 80% with GPs being the most common source of healthcare. However, there is evidence that sex workers do not often disclose their occupation to their GP and also have low uptake rates of key preventive services such as cervical screening and hepatitis B vaccination. About 80% report difficulties attending an appointment, especially those sex workers who work at night. Street sex workers, whose health is often poorest and who may have drug misuse problems, find it particularly difficult to keep appointments.

7.3 Elements of Good Practice

Some specialist services aim to improve primary care registration as part of the specialist service they offer. There are alternative models in place, such as the Transitional Primary Care Team in East London, that provide registration for those refused registration in mainstream primary care. This service is accessible to a number of vulnerable groups including sex workers. The favoured models in major urban areas are dedicated services or outreach models. There are a number of innovative but mostly unevaluated examples of these services in Edinburgh and London. One outreach service in London, Sexual Health On Call (SHOC), has been independently evaluated and has shown that with the additional use of bilingual workers and a dedicated clinic, it has been able to engage large numbers of both migrant street and off street workers, such that over half of its clientele are migrants.

A further approach is the use of mobile clinics that are accessible out of hours, especially at night, though there has been little robust evaluation of such models. The use of cultural mediators and peer educators who are drawn from amongst off-street migrant sex workers has been general practice elsewhere in Europe and has shown promising results in engaging a largely invisible majority with health care.

Broader multiagency partnerships of sex workers, local authorities and health services aiming to reduce crime and violence and promote exit from sex work have also been established in some cities. One such service working with a group of sex workers in Nottingham has shown promising reductions in local crime, increased use of drug misuse services by sex workers, increased access to health screening, and an apparent fall in sexually transmitted infections.

Key elements of good practice have been identified as:

- o Sustainable, joined up multiagency services rather than fragmented single agency approaches
- A broad range and balance of services should be offered that address both sex worker health needs and those of community safety and crime prevention.
- The UK Network of Sex Work Projects has stated that services should be non-judgemental and accept that some sex workers do not wish to exit.
- o Access to specialist medical and other staff.
- Active engagement with sex workers and their networks.

7.4 Secondary Care

No specific interventions have been identified for this group that have had as their objective the reduction of avoidable hospital admissions.

8. Recommendations and Next Steps

8.1 Key National Issues

The National Inclusion Health Board endorsed the following national issues /recommendations below:

- Frequent changes to eligibility for access to free secondary care for overseas visitors (including asylum seekers and failed asylum seekers) present barriers to good access for these groups and training for primary and secondary staff on eligibility issues is needed (**Department of Health**).
- The strong evidence that some GP practices refuse to register vulnerable populations needs to be addressed through the primary care commissioning process, and the NHS Constitution (**NHS England**).
- Responsibility for spreading good practice and training staff in a new, localised health system needs to be clarified (**NHS England & Public Health England**)
- Given the almost absent information for health surveillance for the four groups, a surveillance strategy and supporting data needs to be drawn up/implemented (**Public Health England**)
- The lack of consistent, routine information on health service use and outcomes in the four groups reviewed hampers the development of evidence-based JSNAs, prevents effective local performance monitoring/improvement, and makes research more costly. This is reflected in the almost complete lack of secondary care studies amongst Gypsies and Travellers, asylum seekers and refugees, and sex workers (work is to be taken forward between DH, PHE and NHS earlier review "Hidden Needs"-England based on the https://www.gov.uk/government/publications/effective-health-care-for-vulnerablegroups-prevented-by-data-gaps

8.2 Key Research Issues

There are many promising models in operation serving vulnerable groups across the country but with little evaluation and almost no cost-effectiveness evidence - aside from the homeless models of care. Of around 80 services/interventions selected in the review, only one quarter were evaluated and only 16% independently evaluated. The limited literature on some of the most disadvantaged members of society militates against learning and spreading good, efficient practice against a backdrop of localism.

Discussions on effective ways of filling research gaps have taken place with DH R&D Policy the National Institute for Health Research (NIHR) programmes and a new programme of research is now to be funded based on key research gaps identified below. Discussions with independent research funders are also to be taken forward.

The National Inclusion Health Board endorsed the following recommendations to *research funders and researchers to support further research as follows:*

- Establishing the effectiveness/cost-effectiveness of the following models of service for promoting improved access/use of primary care services on outcomes and use of hospital care: mainstream, outreach and dedicated care in relation to the size of local vulnerable populations served.
- Establishing the most cost-effective mix of professionals and advocates for each model of service in relation to outcomes/avoidable use of hospital care.
- Most of the models of service reviewed have focused on one particular vulnerable group. Some have built their services around several vulnerable groups as they share some features in relation to need, such as a mobile population or language need. Research is needed to help define the most cost-effective organisational solutions.
- The different models of community engagement described require evaluation to identify which are best at enhancing the community's trust of mainstream services and its ability to address its own health needs.
- Robust information on the factors which underlie refusal to register vulnerable patients is needed.

8.3 Spreading Promising Practice

Given new duties to reduce inequalities and the need to act quickly in a challenging economic climate, a guide to *"Promising Practice"*(?URL), based on current evidence will also be published and made available to commissioners, users, and providers.

1. Introduction

The National Inclusion Health Board's Data and Research Working Group identified the need for a literature review that encompasses, with respect to the 4 vulnerable groups (asylum seekers/refugees, Gypsies/Irish Travellers, people who are homeless, and sex workers): a) Interventions (or service models) that improve access to/registration in primary care; b) Interventions which have been shown to reduce the risk of inappropriate admission/readmission to hospital.

What are health interventions?

Interventions in health and social care settings have been defined in a range of ways. Pawson *et al.* (2004) state: "Intervention" is a useful catch-all term in that it captures the totality of activities subsumed within healthcare, but in doing so conflates initiatives that are, methodologically speaking, quite separate. Thus a clinical 'treatment' is not the same thing as a health care 'programme', which is not to be confused with health 'service delivery', which is a different animal from health 'policy'. There are also endless subdivisions within these categories, as when the focus of attention on, say, service delivery switches from "innovation" to "management" to "regulation". With respect to primary care interventions, the NHS National Institute of Health Research has recently seen the term as encompassing 'a range of methods used to promote health, prevent and treat disease or improve rehabilitation or care. It may include the use of: drugs, devices and tests of physical, psychological or surgical therapies and the settings within which they are delivered'. Given the breadth of coverage of the term, this report has focused on: (i) health policies with the stated objectives (as these may provide the context for local interventions); (ii) health and social care interventions implemented in local contexts that provide new approaches to the delivery of services, especially those that improve access to primary care services and prevent acute and inappropriate admission to hospital.

In undertaking this review links have been made to teams who have undertaken complementary work, notably, the Royal College of General Practitioners (Dr Paramjit Gill and Adrian Hegenbarth) and the Prevention Promotion and Provision group (chaired by Dr Nigel Hewett, University College London Hospital's London Pathway homeless team).

2. Methods

An initial scoping study was undertaken in December 2012 which showed the literature to be limited and heterogenous. Further structured searches have indicated that the majority of studies of interventions are small-scale, descriptive and observational, with very few examples of use of robust evaluative methodologies (RCTs, case-control studies, *et al.*). Nevertheless, for each of the four vulnerable groups, interventions have been found that had been evaluated, albeit frequently by the team responsible for implementing the intervention. Some of these studies, notably those relating to interventions for people who are homeless, include cost effectiveness data. The reported lack of studies on service users and of the costs of services has limited this approach with regard to interventions for sex workers.

Search strategies

Search strategies used for the health and social care peer-reviewed journal literature have been highly structured and built around a PICO (Population-Intervention-Comparison-Outcome) framework, enabling search terms to be grouped into thematic sets. All keywords and synonyms have been identified for each element in the PICO framework and searches undertaken for all possible combinations of search terms to maximise retrieval (the search terms have been linked together using logical Boolean operators). Use has been made of specific groups of search terms that locate specific types of literature, including the widely used Cochrane Highly Sensitive Search Strategies for identifying randomized trials in MEDLINE. Other groups of hedges encompass qualitative studies, reviews *et al.* Hand-searching of some key journals has also been undertaken.

Use has also been made in the search strategy of tools such as the Cochrane Guidelines for PH reviews: http://ph.cochrane.org/resources-and-guidance.

The following literature databases have been searched:

Type of source	Databases				
Medical and nursing literature databases	EMBASE	(Excerpta	Medica);	Highwire	Press;
	MEDLINE	(PubMed	Central);	CINAHL,	British
	Nursing Inde	ex			

Literature databases searched

Citation Indexes	Web of Science (Arts & Humanities Index; Social		
	Sciences Index; Sciences Index); SCOPUS (Elsevier)		
Conference proceedings, symposia, seminars	ISI Proceedings; ZETOC (British Library)		
Consolidators of journal literature	Academic Search Complete; Directory of Open Access		
	Journals; EBSCO host; ScienceDirect (Elsevier);		
	InformaWorld; IngentaConnect; <u>Journals@Ovid/OVID</u>		
	SP databases; JSTOR; Literature Online (Proquest);		
	FindArticles (LookSmart); Open J-Gate (4000 open		
	access journals)		
Economics literature	EconPapers (research papers in economics);		
Evidence-based medicine sources	Cochrane Library (systematic reviews and controlled		
	trials); DARE (University of York Centre for Reviews		
	& Dissemination); NHS Economic Evaluation Database		
	(NHS EED) (CRD)/Health Economic Evaluation		
	Database; HTA Database (CRD); TRIP; and the		
	National Institute for Health and Care Excellence		
	collections.		
Grey literature (not elsewhere cited)	DH Data; Kings Fund Database; Health Management		
	Information Consortium (HMIC)		
Psychology literature	PsycARTICLES; PsycINFO		
Social Science/Sociology/Social care	ASSIA (applied social science journals); IBSS		
literature	(International Bibliography of the Social Sciences);		
	REGARD (UK social science research); Social Care		
	Online; Sociological Abstracts; SocINDEX		

Grey literature:

A wide range of grey literature sources has been used to locate relevant interventions, including: statutory sources [PCT Public Health Annual Reports; Joint Strategic Needs Assessments; Local Area Agreements / Local Strategic Partnerships; webpages on the four vulnerable groups on NHS organisation¹ / local authority² websites; Overview & Scrutiny documents; NHS and local authority single equality statements and impact assessments³], national programme documentation (e.g. Pacesetters Programme; NHS Health Trainers Programme; NIHME Mental Health Programme, etc.);

¹ E.g.: http://www.cumbria.nhs.uk/equality-and-diversity/gypsytravellerhealth.aspx
² E.g.: http://www.cornwall.gov.uk/default.aspx?page=28327

³ E.g.: http://www.fenland.gov.uk/article/1843/Traveller-and-Diversity-Section---Equality-Impact-Assessment---Report:

http://www.kingston.gov.uk/information/your council/equalities/equality impact assessments/eqia community _services/traveller_community_support.htm;

reports of policy organisations [such as Equality and Human Rights Commission, Race for Health, RCN, Local Government Association]; and reports of community organisations [such as London Gypsy and Traveller Unit⁴, Friends, Families and Travellers, etc.]. Searches have also been undertaken on the web and Google Scholar using Google advanced search algorithms and subscription sources such as SCIRUS (quality assessed web pages). Several additional sources have been used to identify innovative projects, including NHS Improvement (Accessed at: <u>http://www.improvement.nhs.uk/qipp/Home/Innovation/tabid/181/Default.aspx</u>), NHS Institute for Innovation and Improvement (Accessed at: <u>http://www.institute.nhs.uk/</u>), and grants awarded for new services and innovations in healthcare by the Guy's and St Thomas's Charity.

Type of synthesis

For the <u>peer-reviewed literature</u>, the review has been conducted on the basis of the specification of the inclusion / exclusion criteria for studies to be reviewed (PICOs); screening of abstracts to identify papers for inclusion; accessing full-text versions; and data extraction and presentation or analysis. Within this, the issue of comparators has been addressed (direct vs indirect comparisons, outreach vs non-outreach interventions, etc.). Quality assessment procedures have been considered⁵, using one of the quality assessment tools, such as:

Quantitative studies:

http://www.ephpp.ca/tools.html &

Qualitative studies:

http://www.york.ac.uk/inst/crd/SysRev/!SSL!/WebHelp/6_4_ASSESSMENT_OF_QUALITATIVE_ RESEARCH.htm

At present quality indices have not been applied. Given the limited information available, the use of quality assessment tools has been judged to have limited appropriateness.

Also an attempt has been made to assess wider applicability with respect to relevance, feasibility, sustainability, etc. of the intervention (including views of community groups and staff in specialist services). Only limited use has been made of the international literature where it is judged relevant.

⁴ http://www.lgtu.org.uk/useful-links.php

⁵ These include, for example, the Equity Checklist for Systematic Review Authors and PROGRESS-Plus [disadvantage can be measured across categories of social differentiation, using the mnemonic PROGRESS-Plus: *PROGRESS* is an acronym for Place of Residence, Race/Ethnicity, Occupation, Gender, Religion, Education, Socioeconomic Status, and Social Capital, and *Plus* represents additional categories such as Age, Disability, and Sexual Orientation. See: Campbell and Cochrane Equity Methods Group at <u>http://equity.cochrane.org/</u>]

For example, many of the reported studies of interventions for sex workers are in resource poor countries which may have only limited applicability to the UK context. However, a number of good practice examples of *cultural mediators* and *peer educators* have been drawn from mainland European countries.

Definitions and descriptions of the interventions are set out in the review with respect to the target population (including which of the four vulnerable groups and, where relevant, the size of the local population receiving the intervention), the scope of the interventions covered, including wider determinants of health, and outcomes measures (intermediate / process outcomes and final outcomes where available).

For the <u>grey literature</u>, which has yielded the majority of the interventions, a different but complementary approach has been utilised, that of *realist synthesis*: <u>http://www.ccsr.ac.uk/methods/publications/documents/RMPmethods2.pdf</u>⁶

This methodology attempts to answer the question: 'What works for whom, in what circumstances, in

what respects, and how?'.

The following format has been used for presenting findings:

- Introductory text identifying issues in accessing primary and secondary care
- Description of main service models, including innovatory practice
- Examples of good practice: description of the intervention and findings of evaluations
- Summary: key components of good practice

Quality grading of evaluations

An attempt has been made to prioritise well-described and documented interventions that have been formally evaluated.

In order to help readers assess the quality of evaluations, a quality grading system has been devised that seeks to take account of the robustness and comprehensiveness of the evaluation and whether it was independently undertaken or not. The review has identified evaluations of quality which have been undertaken by teams delivering the intervention so independence is not a necessary requirement of robustness or quality. 4 grades are identified:

⁶ Pawson R, Greenhalgh T, Harvey G, & Walshe K. *Realist synthesis: an introduction. Research Methods Programme Methods Paper 2/2004.* Manchester: ESRC Research Methods Programme, University of Manchester, 2004.

[G1]: Incorporates some assessment of process (intermediate outcomes), user-assessed final outcomes, and cost evaluation (cost effectiveness or return on investment [ROI] type calculations at best, otherwise costs of providing the service)

[G2]: Incorporates some assessment of process and user-assessed final outcomes but no cost data

[G3]: Incorporates some assessment of process and/or final outcomes (not user-assessed)

[G4]: General descriptive accounts of the intervention or expert opinions, but without an explicit focus on evaluation (process or final outcomes). Although descriptive, a significant proportion of grade 4 interventions have been cited as good practice examples and in some cases have been the recipients of awards for innovative practice *et al*.

IE = independently evaluated; NIE = not independently evaluated (this attribution is not relevant to interventions graded 4).

Thus, a grade 1 evaluation independently evaluated would be graded [G1, IE]

3. Findings

3.1. Vulnerable migrants

Definition

Vulnerable migrants encompass a number of groups: asylum seekers, failed asylum seekers, persons with refugee status or humanitarian protection, and irregular or undocumented migrants (those in the country illegally, including those who have entered the country clandestinely and visa overstayers). There is likely to be a spectrum of vulnerability in some of these groups (such as asylum seekers and refugees). Some groups, such as overseas students, may also be vulnerable by virtue of their low registration rates with GPs, and others who are vulnerable because of lack of education, employment skills, or fluency in English.

Policies on refugees and asylum seekers

The most relevant policies to this review on asylum seekers and refugees are those that relate to access to primary and secondary care. GPs have the discretion to accept any person to be either fully registered as an NHS patient or as a temporary resident if they are to be in an area between 24 hours and three months. This includes refugees, asylum seekers, and failed asylum seekers, previous public consultation having highlighted the need for clarity⁷. There is no minimum period that a person needs to have been in the UK before a person can register them. GPs must consider such applications on their merits and decline them only if their patient list is formally closed to new registrations or if the practice has other valid and non-discriminatory reasons for refusing an individual. Moreover, GPs have a duty to provide free of charge treatment which they consider to be immediately necessary or an emergency, regardless of the status of the patient as ordinarily resident or not or registered with that practice.

Charging regulations for secondary care for asylum seekers and overseas visitors have undergone a number of changes over the last decade and have been the subject of much confusion and misunderstanding by healthcare staff and managers, sometimes with tragic consequences. The current regulations for England, published in May 2012⁸, set out eligibility and make it clear that it is the NHS body's duty, not the GP's, to establish entitlement for free hospital treatment. Firstly, a person

⁸ Department of Health (Allocations and Income Generation). *Guidance on Implementing the Overseas Visitors Hospital Charging Regulations*. Leeds: Department of Health, 2012 (October). See:

⁷ According to the Joint Committee on Human Rights' recent report [HL, HC. *Joint Committee on Human Rights. The Treatment of Asylum Seekers. Tenth Report of Session 2006-07. Vol. 1 – Report & formal minutes. HL Paper 81-1. HC 60-1*, para. 154], the responses to a consultation exercise showed strong support for clearer rules on eligibility, clearer definition of what constitutes immediately necessary treatment, and support for disease specific exemptions from charging.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127054/GUIDANCE-October-2012-FINAL.pdf.pdf

granted temporary protection, asylum or humanitarian protection under immigration rules is recognised as a refugee and is exempt from charges.

With respect to asylum seekers and others seeking refuge, persons who have made a formal application⁹ with the Home Office for temporary protection, asylum or humanitarian protection which has not yet been determined is also exempt from charges. Failed asylum seekers – persons who have had their asylum/humanitarian protection application and all appeals rejected – are in a different position. At that point they will become liable for charges for their NHS hospital treatment, even if they have been in the country for more than one year. However, even failed asylum seekers will be exempt if they fall under certain sections of the Immigration and Asylum Act 1999. Failed asylum seekers who are being supported by the UK Border Agency under 'section 4' or 'section 95' of the Act are exempt from charges. Section 4 support is given to those failed asylum seekers taking reasonable efforts to leave the UK but for whom there are genuine recognised barriers to their return home. Section 95 is provided to asylum seekers who have children under the age of 18. A failed asylum seeker who makes a fresh application for asylum, temporary protection, or humanitarian protection will become an asylum seeker again and will thus be exempt from charge again until the new application is considered.

Any particular course of treatment underway when as asylum seeker's application (including all appeals) is rejected, or when a failed asylum seeker stops receiving UKBA section 4 or 95 support, will continue free of charge until that treatment concludes or the person leaves the country. However, NHS bodies must not withhold treatment that is medically considered necessary or urgent in that it cannot wait until the patient can reasonably return home. Thus, immediately necessary treatment from A & E departments or walk-in centres, treatment for certain communicable diseases, family planning services, and compulsory psychiatric treatment are all provided free.

A late change to the regulations concerned the provision of guidance on HIV treatment for overseas visitors¹⁰. Prior to 1 October 2012, only the diagnostic HIV test and associated counselling was free to all overseas visitors. From this date an amendment has meant that HIV treatment (including prescribing of antiretroviral therapy) has no longer been chargeable to any overseas visitors (including people who have no lawful permission to remain in the UK) and is now provided in the same way as treatment for other sexually transmitted infections. This brings England in line with practice in

⁹ Formal applications are those made under the 1951 UN Convention and its 1967 Protocol and also any other request for humanitarian protection, such as some claims made on protection from serious harm grounds under Article 3 of the European Convention on Human Rights.

¹⁰ Department of Health. *HIV treatment for overseas visitors. Guidance for the NHS.* London: Department of Health, 2012 (September). Accessed at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/126981/DH-Guidance-HIV-and-NHS-Charging-fORMATED.pdf.pdf

Scotland, Wales, and mainland Europe. The public health arguments for the change were the reduction in risk of transmission of HIV to people in the UK and the fact that availability of treatment should increase the acceptance of confidential HIV testing. With respect to benefit, the Terrence Higgins Trust estimated that between 660 and 1000 people in the UK were, prior to the change, allowed testing and counselling free but were charged for drug treatment¹¹.

The regulations on charging may change yet again. On 3rd July 2013 the Department of Health launched an open consultation on charging migrants and overseas visitors access to use the NHS¹². The consultation includes plans to: make temporary residents from outside of the European Economic Area contribute to the cost of their healthcare with a levy that then enables them to access NHS services when they need them, or through health insurance or other options; end free access to primary care for all visitors and tourists; more effectively claim back reimbursement from the home countries of patients who are visiting from within European Economic Area; and introduce more practical and easier ways for the NHS to identify whether someone is not eligible for free healthcare. Research has been commissioned by the Department of Health to establish the size of migrant groups, commensurate with these plans.

Access to primary care

The evidence base on vulnerable migrants' registration with GPs and access to primary care services is variable and in some cases inconsistent. Much of it relates to registration levels obtained in crosssectional research studies or surveys, which capture a heterogeneous group of migrants who have been in the country for varying periods of time. Only limited findings are available for cohorts of new entrants or asylum seekers / refugees. Moreover, there has been a focus on some migrant populations who are known to have the greatest health needs - that is, refugees and asylum seekers - and less attention has been accorded to other groups whose health tends to be better but who may, nonetheless, be vulnerable because of low levels of registration and, hence, poor access to primary care services (such as students and long-stay visitors). Finally, a third group, 'undocumented migrants', probably have the worst access but systematic findings for this group are sparse as the group are hidden.

The analysis of large datasets reveals conflicting findings. Firstly, NHS Connecting for Health's Patient Register Data Service compiles yearly data for ONS on what are called Flag 4s: these identify individuals who have registered with a GP in England and Wales as previously living overseas. They may be UK nationals whose previous address was outside the UK and non-UK nationals entering England and Wales for the first time. Investigators have compared counts of Flag 4s and long-term

¹¹ Hawkes N. UK government agrees to fund free drug treatment for foreign nationals with HIV. *BMJ*

^{2012;344:}e1562 doi: 10.1136/bmj.e1562 (Published 29 February 2012). ¹² See: https://www.gov.uk/government/consultations/migrants-and-overseas-visitors-use-of-the-nhs

entrants, then made assumptions about the level of GP registration. For example, between August 2009 and July 2010 a total of 622,178 Flag 4s were registered in England and Wales. Between July 2009 and June 2010 572,000 long-term (for more than a year) migrants entered the UK. The similarity in numbers of new registrants with a previous overseas address and of new entrants during a contemporaneous time period might reasonably be used to argue that the registration of new entrants is high.

However, a recent study using a more robust methodology (record linkage) found surprisingly low levels of GP registration amongst a particular cohort of new entrants¹³. This retrospective cohort study successfully linked the records of 252,368 new entrants to the UK whose entry was documented by the port health tuberculosis screening process at Heathrow and Gatwick in 2009/10 with the Personal Demographics Service (PDS) database which records registration with a GP practice within the UK. Only 32.5% of these individuals were found to be registered. Exposure variables included age, gender, nationality, immigration status, and year of entry. Women were more likely to register than men (RR ratio 1.44, 95% CI 1.41 to 1.46); compared to those from Europe, individuals of nationalities from the Americas (0.43 (0.39 to 0.47)) and Africa (0.74 (0.69 to 0.79)) were less likely to register. Students (0.83 (0.81 to 0.85)), long-stay visitors (0.82 (0.77 to 0.87)) and asylum seekers (0.46 (0.42 to 0.51)) were less likely to register with a GP than 'other' migrant groups (mainly individuals entering with work visas). In addition, the over 65s were less likely to register and year of entry was associated with registration (individuals entering in 2010 having less time to register than those entering in 2009). Asylum seekers, the group with the greatest health needs, had the lowest proportion registered (19.1%). As port health services only screen entrants from countries with a high incidence of tuberculosis, the findings can only be generalised to these at-risk populations.

Other reviews and studies have reported substantially higher rates of GP registration for asylum seekers and refugees though not directly comparable as most are samples of these populations in particular areas (who may have been living in the country for varying periods of time) rather than cohorts of new entrants. The *Survey of Refugees Living in London*¹⁴ (1,007 interviews with refugees living in London) found nearly all the refugees (98%) were registered with a GP and the GP surgery/doctor was the most preferred service for treatment of illness by 88% of respondents, the second most preferred service being A & E/hospital (7%), followed by walk-in centres (3%). The government's *Survey of New Refugees*¹⁵ (all people over the age of 18 who were granted asylum,

¹³ Stagg HR, Jones J, Bickler G, Abubakar I. Poor uptake of primary healthcare registration among recent entrants to the UK: a retrospective cohort study. *BMJ Open* 2012;2:4 e001453 doi:10.1136/bmjopen-2012-001453

¹⁴ Ipsos MORI Social Research Institute. A survey of refugees living in London. Report for the Greater London Authority. Ipsos MORI, 2010 (September).

¹⁵ http://discover.ukdataservice.ac.uk/catalogue?sn=6556#variables

humanitarian protection, or discretionary leave to remain between December 2005 and March 2007, questionnaires being sent out within one week of the asylum decision) (n=5,678) found that 93.2% were currently registered with a GP, though only 52.8% were currently registered with a dentist. Thus, this study, a cohort of asylum seekers tracked through to a positive asylum decision, yields a much higher registration rate than the HPA's new entrants study (in which only 19.1% of 3071 asylum seekers were registered).

Amongst patients born abroad presenting to an inner-city London infectious diseases department, 81.1% (of 43) had permanent registration with a GP, though 60.4% had been admitted through A & E^{16} . Amongst the international migrants in the study, not having a GP was strongly associated with being overseas born, being a refugee/asylum seeker, being a new migrant, not having English as a first language, and being in the UK for ≤ 5 years.

There is now an extensive evidence base on the multiple barriers experienced by asylum seekers and refugees in accessing GP treatment. The Joint Committee on Human Rights¹⁷ reported the following problems:

- the difficulties experienced in registering with a GP (the burden of documentation required to prove address and/or identity, including lack of address for rough sleepers or those in very temporary accommodation)
- unwillingness of practices to register asylum seekers for time/resource reasons
- eligibility mistakes made by receptionists and others in GP surgeries
- a shortfall in the availability of interpreting services.

One of the consequences of these difficulties is an increased reliance on A & E services as a substitute, increasing healthcare costs and pressure on A & E services.

A large number of research studies have documented similar difficulties. This evidence base has been comprehensively reviewed, including rates of GP registration $(2007)^{18}$. Varying levels of GP registration have been reported (a range of 90-98%) and some GPs offer only temporary registration, although data are frequently unavailable on this. There is also some evidence of higher use of A & E

 ¹⁶ Cooke G, Hargreaves S, Natkunarajah J, *et al.* Impact on and use of an inner-city London Infectious Diseases Department by international migrants: a questionnaire survey. *BMC Health Serv Res* 2007; 7: 113.
 ¹⁷ *Ibid.*, HL Paper 81-1 & HC 60-1, pp. 51-54.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127393 ¹⁸ Aspinall PJ. A review of the literature on the health beliefs, health status, health needs, and use of services in the refugee and asylum seeker population and of appropriate health and social care interventions. Health ASERT Programme Wales. Report No. 4. Cardiff: Welsh Assembly Government, 2006 (November). See: chpt. 12.1. Rates of GP registration & use; 12.2 Barriers to access; and Communication barriers, pp. 47-51.

services amongst asylum seekers. Nearly all the studies of asylum seekers and refugees reported identified barriers and problems in accessing health services and a very wide range of access issues are identified in both refugee and asylum seeker accounts and in those of providers and other health care professionals. The type and frequency of barriers varies across client groups and services. Vulnerable migrants may be uncertain about their entitlements to healthcare. There is substantial evidence that communication (especially relating to language) is a major barrier in accessing primary care and other services, especially out of hours services¹⁹. Some asylum seekers may fear that declarations about their health to health services will be reported to the immigration authorities. There may also be service-provider barriers to access for migrants, including a reluctance to register and a lack of knowledge about eligibility rules. A lack of access to primary care may have several repercussions: delayed treatment of transmissible infections and conditions, endangering wider population health; inappropriate use of more costly emergency and inpatient care; the barrier posed by non-registration to hospital and other referrals; and lack of engagement with health promotion/prevention activities that take place in general practices.

A more recent investigation in a London refugee drop-in centre of the experiences of refugees and asylum seekers themselves in accessing and using GP services has reported many of these barriers²⁰. With respect to access, the main problems were locating practices and then language difficulties when arriving at them. This led to difficulties both registering and making an appointment. Once in the consulting room language difficulties were a significant barrier to effective healthcare (including the failure of interpreters to attend and their non-availability for emergency appointments). Other difficulties included poor continuity of care, the experience of not having the same doctor in the practice, a preference for the use of the same interpreter with each consultation, a perception that asylum seekers were a burden on the healthcare system and resources, and the reported tendency of GPs to prescribe medication rather than to listen to them or provide appropriate advice. Some respondents preferred to use family and friends as interpreters (who were concerned about trusting professional interpreters because of inter-communal violence in their country of origin) while others did not. However, there was no evidence that women were concerned about gender discordant interpreters²¹ although other studies have reported such concerns²². The study also found worse access to GPs for those refugees without support from friends, family and refugee agencies.

¹⁹ See, for example, Health Protection Services. *Migrant Health. Infectious diseases in non-UK born*

populations in the UK. An update to the baseline report – 2011. London: Health Protection Agency, 2011. ²⁰ Bhatia R & Wallace P. Experiences of refugees and asylum seekers in general practice: a qualitative study. BMC Family Practice 2007; 8: 48.

²¹ Bhatia R. Wallace P. Experiences of refugees and asylum seekers in general practice: a qualitative study. BMC Family Practice 2007: 8: 48.

²² Ngo Metzger Q, Massagli MP, Clarridge B, Manocchia M, Davis RB, Iezzoni A, Phillips RS. Linguistic and cultural barriers to care. J Gen Intern Med 2003; 18: 44-52.

Promising/good practice in primary care

A number of studies have attempted to define best practice in primary care for migrants. A Faculty of Public Health briefing²³ made recommendations to improve asylum seekers' health. Eling²⁴ added further examples of good practice, the following combined list being advocated by the SE Migrant Health Study Group:

- Specialist centres and support teams offering multidisciplinary approaches for asylum seekers, for example, including mental health services and specialists in services for torture survivors, and focusing on young, separated refugees and asylum seekers
- Dedicated salaried GPs and projects to increase registration within existing practices
- Specific enhanced services, monitored by key performance indicators
- GUM clinics dealing with sexual violence, female genital mutilation and HIV/AIDS
- Challenging stigma through diversity-awareness training
- Annual notifications to PCTs and local authorities from the Home Office when changes occur in new arrivals

Interventions to increase GP registration

A wide range of interventions have been used to increase GP registration. Those embedded in service models are discussed below.

Primary care service models

With regard to primary care services, a recent review utilises a tripartite framework of <u>gateway</u>, <u>core</u> and <u>ancillary services</u>²⁵. <u>Gateway services</u> facilitate entry into primary care by identifying unregistered patients and carrying out health assessments, typically undertaken by nurse-led outreach services and specialist health visitors. <u>Core services</u> provide full registration and may be provided by dedicated practices or by mainstream practices, with or without additional support. <u>Ancillary services</u> are those that supplement and support core services' ability to meet the additional health needs of this group (such as language and information services, specialist mental health services, services for

²³ Faculty of Public Health. *The health needs of asylum seekers*. *Briefing statement*. Faculty of Public Health, 2008.

²⁴ Eling A. Asylum seeker, refugee and vulnerable migrant services. Mapping and best practice report and recommendations. 2009.

²⁵ Feldman R. Primary health care for refugees and asylum seekers: A review of the literature and a framework for services. *Public Health* 2006; 120: 809-816.

survivors of torture and organized violence, and targeted health promotion). This framework is useful for looking at the effectiveness of primary health care services as a whole for refugees and asylum seekers. In general there is little systematic analysis and evaluation of the different service models and interventions.

<u>Gateway services</u> - including nurse-led outreach services - are usually only found in those areas where there is a concentration of refugees and asylum seekers (mainly London). Those in Lambeth, Southwark and Lewisham and Barnet include nurse-led clinics in hostels and health centres and a dedicated clinic at an NHS walk-in centre and offer such services as full health checks, treatment, liaison with GPs to facilitate registration, and advice and information. The Health Support Teams of Westminster and Kensington and Chelsea PCTs have had outreach teams, over 70% of unregistered patients seen by such teams being registered with GPs on discharge from the team²⁶. Another model is that of specialist health visitors for asylum seekers employed by PCTs. In the Northern and Yorkshire NHS region, half of the health authorities contacted reported that a health visitor facilitated GP and dentist registration for asylum seekers.

<u>Core services</u> – full registration with comprehensive health checks and standard primary care – may be provided in dedicated practices or mainstream practices with no specialist provision. Dedicated practices (frequently nurse-led) may serve a local population of asylum seekers or particular centres and hostels and offer a wide range of services such as tuberculosis screening and vaccination. In dispersal areas they may be linked to housing providers and social care and other services. Although evaluations are few, dedicated practices are effective where there are large numbers of refugees and asylum seekers. Other models for delivering core services include enhanced services (formerly local development schemes) whereby practices receive incentives to fully register and improve provision for refugees and asylum seekers; the attachment or appointment of specialist staff (such as a doctor, nurse, or administrative support); and the provision of a dedicated additional service outside scheduled clinical sessions. There is little in the way of robust evaluations of these different service models.

<u>Ancillary (or supplementary) services</u> come in many different forms, including PCT teams and advocacy/health promotion projects. Feldman (2006)²⁷ has categorised these services into 3 groupings: facilitating communication and information; specialist care, especially in mental health and for survivors of trauma; and training and support for health professionals. With regard to the first the need to build capacity in community-based organizations is seen as crucial. The range of

²⁶ Burchill J. Annual review 2003 of Health Support Team: Westminster & Kensington & Chelsea Primary Care Trusts. London: Westminster & Kensington & Chelsea Primary Care Trusts, 2004.

²⁷ Feldman R. *Ibid.*, 2006.

interpretation, translation, and information issues to which such organizations can contribute is substantial: cross-agency collaboration in the provision of services, the provision of information to plan services, recruitment of bilingual staff from refugee communities, the provision of bilingual link workers who provide advocacy for patients (although little use of such workers is reported for asylum seeker and refugee populations), and the facilitation of appropriate written materials. The provision of mental health services for survivors of torture and organized violence is widely regarded as inadequate for the needs of asylum seekers and refugees. The Scrutiny Report on Access to Primary Care in London²⁸ indicated that to meet mental health needs adequately, PCTs would have to increase their allocation two-or three-fold. The range of current provision includes a limited number of specialist services for asylum seekers located in mental health trusts or run by independent bodies, trauma services that include survivors of torture or violent conflicts in their patient population, the Medical Foundation for Victims of Torture, inter-agency partnerships developed specifically to provide services for this group, and provision within specialist general practices of in-house sessions with community mental health nurses or counsellors. The third category - training of health workers has been identified as an important need by both asylum seekers and professionals, especially in relation to mental health, understanding the asylum system and cultural awareness.

A number of reports have highlighted good practice examples and different service models²⁹. In addition, some components of these interventions have been accorded importance (such as patient-held records).

Examples of good/promising practice interventions in primary care settings

Gateway services

The <u>Health Advocacy Service in Hounslow³⁰</u> was a three-year (2006-08) pilot project funded by the King's Fund. Two half-time bilingual advocates conducted individual and group outreach to identify

²⁹ Eling J. *Primary care services for asylum seekers in Lambeth, Southwark and Lewisham 2005. Service Evaluation and Recommendations*. London: Lambeth NHS Primary Care Trust, 2006 (May). Accessed at: http://www.threeboroughs.nhs.uk/document_view.php?PID=0000000206&DID=00000000000000000092; Eling J. Asylum Seeker, Refugee, and Vulnerable Migrant Services. Mapping and Best Practice Report and Recommendations. London: Hetherington Group Practice, 2010 (March). Accessed at:

²⁸ London Assembly, Mayor of London. *Access to primary care: a joint London Assembly and Mayor of London scrutiny report.* London: Greater London Authority, 2003.

http://www.maternityaction.org.uk/sitebuildercontent/sitebuilderfiles/new_refugee_and_migrant_services_mapp ing_and_best_practice_reportv3.pdf; Feldman R. Primary health care for refugees and asylum seekers: a review of the literature and a framework for services. *Public Health* 2006; : 809-16. See also: Gorton S. *Guide to models of delivering health services to homeless people*. London: Crisis, 2003.

³⁰ This description draws on: Feldman R. *Guidance for Commissioning Health Services for Vulnerable Migrant Women*. Maternity Action & Women's Health and Equality Consortium. February 2012.

asylum seekers in Hounslow and to help them register with a specialist practice for refugees and asylum seekers. When the specialist practice closed, the advocates encountered reluctance by some mainstream practices to register asylum seekers. Outreach took place at a weekly women's group, a children's centre, the local further education college which ran a programme for new communities, and in hostels for asylum seekers. Advocates also provided assistance with problems other than GP registration and contributed to PCT training on needs of refugees and asylum seekers.

The project was evaluated by Rayah Feldman in 2008³¹ using mixed methods of data collection comprising examination of documents and field research through qualitative interviews and participant observation. The advocates were also requested to keep reflective diaries to record and comment on significant experiences in the course of their work. The evaluation showed that the health advocates were meeting a high level of need, supporting the registration of 357 refugees and asylum seekers between June 2006-December 2007. When the specialist GP practice closed, the advocates encountered difficulties with registering asylum seekers and refugees with mainstream GP services, including a widespread reluctance to use interpreters. The project did find that some practices were more sympathetic to the registration of refugees and asylum seekers as a result of their work. Feldman concluded that: 'Health advocates are an important part of the PCT's policy towards refugees and asylum seekers but their lack of status in the hierarchy makes their role in changing the attitudes and behaviour of primary care staff difficult'. The evaluation considered that their work should be both sustained and, if possible, extended. **Grade [G2, IE]**

Service models that seek to ensure comprehensive GP registration and initial health screening

GP registration is clearly of central importance to the health of asylum seekers and refugees given the documented difficulties of achieving this and the need for initial/additional health screening. As housing providers for asylum seekers are not contractually obliged to ensure that asylum seekers get registered with GPs, specific interventions are needed to facilitate this and initial health checks.

The new entrant health check model is exemplified by the <u>Refugee Health Team LSL's New Entrant</u> <u>Health Check Project³²</u>. The Refugee Health Team LSL is a multidisciplinary team working across Lambeth, Southwark, and Lewisham which provides health care services to asylum seekers and refugees and also seeks to improve access to health care. The team aims to address barriers preventing

³¹ Feldman R. Evaluation of Hounslow Health Advocacy Project for Refugees and Asylum Seekers. 2008 (April). Accessed at: http://www.maternityaction.org.uk/commissioningguidance.html

³² For documentation, see: 'Supporting assessment through an extended new patient check'. Accessed at: http://www.migranthealthse.co.uk/sites/default/files/0315111Extendedhealthcheck.pdf.

access to health care, support the development of appropriate primary care services, and ensure that primary care practitioners are aware of issues affecting asylum seekers and refugees.

In the LSL setting the new entrants' model comprises a collaboration between: (i) the Refugee Health Team LSL; (ii) the SE London Health Protection Unit; and (iii) four Lambeth GP practices, all of which are relatively large, have practice nurse capacity, and are able to make the time required for additional training and planning.

The specific objectives of the model are:

- To increase awareness of TB and other infectious diseases (HIV, viral hepatitis) amongst primary care staff as well as communities at risk
- To promote more rapid diagnosis and treatment of active TB in new entrants, thus reducing the risk of transmission as well as benefiting individuals with the disease
- To ensure new arrivals are systematically offered immunisations which bring their immunisation status in line with Health Protection Agency guidelines, as soon as possible after registering with a GP surgery
- To promote awareness of HIV and viral hepatitis amongst new arrivals and facilitate access to testing services
- To ensure that new entrants have a thorough assessment of their general health status and their needs so that these are addressed
- To promote culturally sensitive assessments using interpreting services where necessary

The LSL Project documentation indicates an upcoming evaluation, to be carried out by several steering group members, that will identify whether the new entrant health check model is manageable in general practice settings and can be extended across Lambeth and SE London: all patient data will be collected on the EMIS GP practice computer system & will be analysed at completion of the project (when 200 checks have been completed) in terms of outcomes such as: percentage of patients opting to participate; numbers of screening tests (HIV, hepatitis, STIs) carried out; numbers referred to TB clinic; numbers of cases of communicable diseases identified, treated or referred, and numbers of vaccinations given by age group. A practice staff satisfaction survey will be undertaken on completion and a patient satisfaction survey with a sample of patients during the study. A log will be kept of difficulties with the process & a cost analysis (total cost & cost by outcome) will be undertaken on completion. To date no evaluation has been published³³.

Grade [G4]

³³ Personal communication, Dr Judith Eling.

Clearly, this model is better adapted to those areas which have large populations of new entrants (asylum seekers, refugees, and other migrants). Elements of the model have been adopted by a few authorities across the country. <u>Sandwell PCT's Cape Hill Medical Centre</u> has an Alternative Provider Medical Services (APMS) contract to provide medical care for asylum seekers and refugees. The practice's nursing team carry out extended "new patient checks" on this group, using an adapted template that applies Read codes to all relevant outcomes of the process. A health care assistant does the first part and a nurse practitioner or practice nurse the second part, the whole process taking about one hour³⁴.

One novel approach to ensure GP registration - frequently cited as best practice - is the <u>Sheffield</u> (formerly South Sheffield) PCT service dedicated to asylum seekers, based in a PCT Managed Service model. The Sheffield service runs a minibus service to physically take newly arrived asylum seekers to their first appointments, and to the follow-up appointment two weeks later. This relies on the close cooperation of housing providers who provide lists of new arrivals each week. The effective liaison with housing providers that the Sheffield service has developed ensures that every new arrival does register with a suitable practice, not necessarily the Sheffield PCT's specialist practice at the Central Health Centre in the centre of Sheffield run by dedicated GPs & nurse team. Other services (including Hull: 'Hull has a problem with attendance at the arrivals' health screening, especially amongst single men'³⁵) report a problem with initial GP registration/screening. **Grade [G4]**

Separate stand-alone services, whether specialist practices for asylum seekers/refugees or a generic vulnerable population

This model comprises specialist, dedicated GP practices. Under Personal Medical Services Schemes (PMS), practices can bid for extra resources to support their work in looking after asylum seekers and refugees. Patients are usually registered for a designated period. Such practices are viewed as a solution in areas of first settlement where there are concentrations of refugees. In some areas these practices also register other vulnerable groups such as homeless people.

There are several examples of dedicated practices: Sheffield PCT's Central Health Centre, Newham (transitional practice for any patient who has difficulties registering with a GP); Hackney (Sanctuary Practice for asylum seekers and homeless people) Huddersfield (Whitehouse Centre), Stockton-on-Tees (Arrival Practice), and Fernbank Medical Centre, Glasgow (combined with 50% of patients from the general population).

³⁴ See: <u>http://dro.dur.ac.uk/9300/1/9300.pdf</u> (pp. 40-41 for the 'extended health check').

³⁵ <u>http://dro.dur.ac.uk/9300/1/9300.pdf</u> (p. 39).

The <u>Sheffield PCT's Central Health Centre</u> has already been mentioned. In 2002 the South Sheffield PCT (now Sheffield PCT) set up a service dedicated to asylum seekers, led by a nurse consultant & based in a PCT Managed Service model (noted in 2010 as intending to become an Alternative Provider Medical Services (APMS) provider). The service, still managed by the nurse consultant, has one f.t.e general practitioner (3 part-time GPs), 2 nurse practitioners, one health visitor/'families nurse', two family support workers (recruited from the refugee population, bi-lingual, and community-based & supervised by the health visitor), and a linked counselling and mental health team. Examples of best practice cited include the enhanced Personal Health Record, provision of funded training and support sessions for the interpreters, TB screening done using the cost-effective 'Quantiferon Gold' test (does not depend on return visits for reading the results) rather than traditional Mantoux test, and the service has a clear policy for writing medical reports (the three GPs having had basic training from the Medical Foundation to enable them to recognise cases with a history of torture needing further assessment). **Grade [G4]**

The <u>Whitehouse Centre in Huddersfield</u> is a PMS practice which comprises 4 GPs, 2 nurse practitioners, and a Practice Nurse. People can register with the practice if they are: homeless; living in temporary accommodation; a recently arrived asylum seeker/refugee; or if they are having problems with drugs or alcohol. Services/clinics include a clinic for baby and pre-school immunisations and counselling (provided in-house and available on the NHS via a specialist counsellor). The practice deals with all asylum seekers as they arrive in the city. No independent evaluation has been identified. **Grade [G4]**

<u>The Arrival Practice, Stockton-on-Tees</u>, has 3 GPs and 2 practice nurses. Its services and clinics include a child health surveillance clinic and minor surgery clinic. The practice provides primary medical care services to people seeking asylum and refugees living in the North Tees Primary Care Trust area. The current registered population comprising 1,421 patients. The North East Primary Care Services Agency (NEPCSA), in conjunction with NHS Stockton-on-Tees, is currently (December 2012) undertaking a review of the Arrival Practice. **Grade [G4]**

The Sanctuary Practice for asylum seekers and refugees in Hackney: This is an APMS (Alternative Provider Medical Services) practice established in 2002 and provides health care to asylum seekers and refugees living in temporary accommodation. Working closely with interpreters and advocates, it assesses their health needs, provides appropriate screening and ensures this information is passed on to practices where they subsequently register. The practice has developed partnerships with local voluntary sector organisations, which play an important role in the health and social care of refugees. Recently the practice has expanded its role to offer services for homeless people and those with problems of substance misuse. **Grade [G4]**
<u>Fernbank Medical Centre, Glasgow</u>³⁶ is a GMS practice located in the Greater Glasgow and Clyde Health Board which has a 50% asylum seeker population, other migrants 1.5%, and with the remaining 48.5% local patients (out of a practice population of 6,924). The service was started to relieve pressure on other local practices since Glasgow became a dispersal area in 2000. The approach has been to provide a service integrated with the mainstream, the local population and asylum seekers being seen together in the same practice. The team comprises 1 GP partner, 3.7 salaried GPs, 2.5 practice nurses, 1 healthcare assistant, 5.5 receptionists, and 1 practice manager. The practice provides GMS registration and services for all patients and healthcare for the Scottish Asylum Seeker Induction Service (which houses 140 patients and involves 30 consultations a month). **Grade [G4]**

Locally Enhanced Services

GPs are contracted to provide core (essential and additional) services to their patients. Enhanced Services are the extra services they can provide on top of these which plug a gap in essential services or deliver higher than specified standards, with the aim of helping PCTs reduce demand on secondary care³⁷. Enhanced services '...expand the range of services to meet local need, improve convenience and extend choice'. The Department of Health commissions and updates enhanced services. Each year, where new priorities for new services to be delivered by GP practices are identified, these can be commissioned, either through national contractual change or primary care service frameworks to support PCTs in local commissioning. There are three types of enhanced service: Directed Enhanced Services (DES) which must be provided or commissioned by the PCT for its population; Local Enhanced Services (NES), services to meet local needs, commissioned to national specifications and benchmark pricing.

A number of Local Enhanced Services and contracted-out arrangements have been set up to meet the needs of asylum seekers and refugees:

<u>NHS Nottingham City</u> commissions a locally enhanced service (LES) for refugees and asylum seekers. GP practices are required to have a minimum of 10 asylum seekers or refugees to be eligible to take part with a payment given for every 10 consultations with asylum seekers or refugees. Failed asylum seekers, including those receiving section 4 support whilst awaiting departure from the UK are not eligible for payment under the LES. Between 1st April 2008 and 31st March 2009, there were

³⁶ Details are taken from Eling J. Asylum seeker, Refugee, and Vulnerable Migrant Services. Mapping and Best Practice Report and Recommendations. March 2010. Accessed at:

http://www.maternityaction.org.uk/sitebuildercontent/sitebuilderfiles/new_refugee_and_migrant_services_mapp ing_and_best_practice_reportv3.pdf

³⁷ PCTs were abolished on 31st March 2013 as part of the Health and Social Care Act 2012, their work being taken over by clinical commissioning groups.

more than 6000 consultations claimed for under the LES by 28 GP practices. The numbers of consultations ranged from 10 to 950 over a year. There were three practices - in Sneinton, St Ann's and the Meadows - that claimed for more than 500 consultations. To date, the LES has not been evaluated to assess the effectiveness and standard of care asylum seekers and refugees are receiving. **Grade [G4]**

<u>NHS Kensington and Chelsea</u> has a Locally Enhanced Service for asylum seekers and refugees in which 23 practices in the PCT participate. The practices are paid a retainer per annum and a fee per asylum seeker or refugee patient (up to 4 years after being granted refugee status). In return they have to comply with a service specification which includes providing an extended new patient check, using interpreters, booking 20 minute appointments and practice staff undergoing training in refugee health related issues. Until funding was withdrawn there was also a link worker who rotated around the practices and provided housing and related advice. The cost of the scheme is £1000 per practice per annum plus £100 per patient per annum. **Grade [G4]**

In <u>Sandwell PCT</u>, the Cape Hill Medical Centre has an APMS (Alternative Provider Medical Services) contract to provide care for around 1200 asylum seekers and refugees in the Sandwell PCT. The contract between Pathfinder Healthcare Developments (PHD) Ltd, a Community Interest Company, and the PCT is designed to provide optimum care for this group, with 20 minute appointments built into the contract. It is based on an 'enhanced capitation fee' of £120 paid for asylum seekers and refugees within 18 months of arrival. The nursing team carry out extended 'new patient checks' on the asylum seeker/refugee population. **Grade [G4]**

Other components of good practice:

(i) Interpreting services: Training and support services and other models

Language/interpreting is one of the issues consistently identified amongst barriers to accessing health care services by the SE Migrant Health Study Group. Feldman (2008) also found 'a widespread reluctance to use interpreters in many GP practices in the (Hounslow) PCT', contending that there are frequently no interpreting services to assist with registration or a refusal to book such services. A range of language support strategies may be used by GP practices, including bilingual staff (clinic staff and receptionists); registers of bilingual staff to act as interpreters; link and support workers; advocacy workers and agencies; community volunteers; reasonable adjustments; face-to-face interpreting; and telephone interpreting (Stallabrass 2011)³⁸. Each of the strategies has advantages and limitations and consideration should be given by commissioners to those favoured by patients and

³⁸ Stallabrass S. *Commissioning Framework for Language Support*. NHS East of England & East of England Local Government Association, 2011.

practitioners. Amongst good practice examples, the training and support sessions for interpreters provided by <u>Sheffield PCT</u> dedicated service for asylum seekers provides has been reported as exemplary practice, though no further information/evaluations have been identified. Also, the East of England <u>INTRAN partnership</u> has been cited as a good practice example which has been internationally recognised and has received national awards for procurement³⁹. INTRAN is a multi-agency not-for-profit partnership providing language services throughout the Eastern region: it operates by commissioning different interpretation/translation agencies to provide their services to INTRAN partners and also provides training for partner organisations. **Grade [G4]**

(ii) Patient-held records

Patient held medical records for asylum seekers and refugees have a history going back to the 1990s. Jones and Gill (1998) argued that the Department of Health needs to develop patient held medical records for this group and that healthcare facilitators should be recruited from each specific refugee population who could help to provide these records with an accurate and detailed medical history. In a House of Lords Debate on asylum seekers⁴⁰, Lord Hunt expressed the view: 'There is no doubt that hand-held patient records are the most appropriate method for dealing with the problem referred to (asylum seekers who are pregnant) and for recording health information. The asylum seeker would keep the hand-held record and take it to health appointments... Many areas have developed their own hand-held records for issue to asylum seekers. My department is working with front-line staff on the development of a national record'. In their response to the Government's consultation on the White Paper *Save Haven, Secure Borders*, the Refugee Council (2002) states: 'Important, relevant information gathered at the initial health assessment should not be lost and Hand Held Records should be established to ensure continuation of care, avoid duplication and to ensure that information gathered is not lost'.

Some early adopters of patient-held records are documented. Penny (2002) provides a comprehensive report on client held records for people who are homeless or asylum seekers and a Client Health Records booklet then being piloted by Luton NHS Primary Care Trust. A hand-held record was also developed by the <u>Suffolk asylum team</u> (Local Health Partnerships NHS Trust and Suffolk Primary Care Groups (2001)) at this time in the form of a comprehensive booklet. The aim of this patient held record is to provide a health needs assessment that can be utilised by all health service providers. It is designed to provide information to the patient, general practitioners, dentists, opticians, hospitals and other service providers, identify health needs, needs for disease prevention services, care given, and to provide continuity of care when asylum seekers are dispersed. Each page contains a different

³⁹ Feldman R. Guidance for Commissioning Health Services for Vulnerable Migrant Women. Maternity Action

[&]amp; Women's Health and Equality Consortium, 2012 (February).

⁴⁰ (Lords Hansard 2002a)

assessment or record: Personal information; emergency information; support workers; medical history; TB screening; immunisations; lifestyle assessment; practice nurse assessment; dental assessment/treatment; optical assessment/treatment; information about health services, appointments/record of visits; and a care plan. Grade [G4]

Gorton (2003)⁴¹ describes the use of client-held records by the <u>Croydon Homeless Health Team</u> for asylum seekers. The record was developed through consultation with practice nurses, specialist TB nurses, and others, and encompasses some specific information needs for asylum seekers including female circumcision and experience of rape and/or torture. Gorton notes that the client held records are 'currently being evaluated'. She also notes their use for refugees and asylum seekers by the Westminster Health Support Team: 'They find that they are well used by asylum seekers and refugees and by families and less so by the single homeless population...may be because asylum seekers and refugees are more used to holding onto important documents', again noting that the team has done an evaluation of the client-held records. Gorton's overall conclusion is that: 'The general picture from evaluations has been that they are not very successful with people who are homeless but that they are an effective tool to use with refugees and asylum seekers'. **Grade [G4]**

Throughout 2003 the Department of Health undertook work on a national patient held record for asylum seekers and refugees, including a workshop for NHS staff from across the country. The content was finalised and despatched to the first of the induction centres in East Kent. Following a consultation exercise with health care professionals who regularly work with asylum seekers and refugees which ran between late April and mid May 2004, the adult personal health record for asylum applicants and refugees was revised, this second edition being based on suggestions gathered during the consultation period. Improvements included the record's structure and the addition of specific pages on confidentiality and consent. A Department of Health patient-held record for asylum seeker and refugee children was also developed, the London Standing Conference (Children's Group) contributing to the development of this record⁴². 'Patient instructions' were translated into the major languages (Albanian, Arabic, Farsi, French, Kurdish, Pashto, and Somali). All asylum-seekers residing at Induction Centres are issued with a hard copy of this record but the patient-held record is also available to be used nationally.

The record contains details of the initial health assessment, any other health care appointments undertaken while at the Induction Centre, and contact details of the health care staff that the asylum

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/International/AsylumSeekersAndRe fugees/DH_4080751 [Patient-held record for asylum-seeekers and refugees. Last modified: 8 February 2007]

⁴¹ Gorton S. *Guide to models of delivering health services to homeless people*. London: Crisis, 2003 (pp. 29-30). ⁴² For copies of the adult and children patient-held records for asylum seekers and refugees, see:

seeker has seen. Where possible, language and interpretation needs are also recorded. The asylum seeker takes the patient-held record with them on dispersal, a copy of their records also being filed at the Induction Centre. There is space in the patient-held records for input in dispersal areas. Copies of other health records or letters given to the asylum seeker can also be hole-punched and inserted into the record's wallet. Any details entered into the patient-held record must be discussed with the asylum seeker to ensure informed consent and reduce the risk of confidentiality breaches.

Comprehensive reports on the utility of this intervention are few: One recent study⁴³ states that 'best practice points to the adoption of a local Personal Health Record, similar to that used in Sheffield, with local information set out in all the main languages'. This is one of several examples of best practice at the Sheffield PCT dedicated asylum seeker service and is a modified version of the patient-held record now given to all asylum seekers when they first arrive at induction centres. It also states that 'Hull asylum seekers do hold these, but they are seldom used' and that 'NHS Hull should adopt the Sheffield model of the Personal Health Record'. The cost of preparation and printing of local information for insertion into the supplied (blue book) loose-leaf record has been estimated at £2,500 or less.

There is a paucity of formal evaluations of patient-held records for asylum seekers and refugees. As with Gypsies/Travellers, the rationale for their use is that this group is a frequently moving population. Moreover, many asylum seekers and refugees may not have skills in English, making it difficult to convey information about their health to health and social care professionals. Hand held medical records have only been formally tested in other populations, including maternity services. One RCT reported that women holding their own notes felt more in control than those holding only co-operation cards but there were no differences in health outcomes or health behaviour (Elbourne *et al.*, 1987). Another RCT with patients with mental illness showed no effect on patient outcomes or admission rates and take-up amongst patients was poor (Warner *et al.*, 2000). A further RCT of hand held records in radiotherapy patients concluded that they made no difference to patient outcomes (Drury *et al.*, 2000).

Interventions which have been shown to reduce the risk of admission/readmission to hospital

There have been relatively few interventions focused specifically on asylum seekers and refugees with these specific aims. Clearly, the good practice models relating to primary care may help to reduce inappropriate hospital admissions. One research study showed that the dominant mode of referral by patients to an inner city infectious diseases department was self-referral through the A&E

⁴³ http://dro.dur.ac.uk/9300/1/9300.pdf

Department⁴⁴; another study reported most patients with tuberculosis at one London hospital being admitted acutely ill via self-presentation to the A&E Department, most previously undiagnosed⁴⁵. Those interventions that specifically address homeless asylum seekers/refugees are discussed in the section on interventions for homeless persons.

Key issues for this group concern asylum seekers' and practitioners' understandings of eligibility, especially access to maternity care. The entitlements of asylum seekers and refugees to secondary care are complex and different to those to primary care and have undergone a number of changes in recent years following challenges in the courts. Some categories of migrant are liable to be charged for secondary care while others are not (see 'policy section' above). Moreover, some medical conditions are exempt from charging.

Maternal care has been a recurrent concern for asylum seekers, refugees, and newly arrived migrants⁴⁶. During the period 2006-8 there were 28 women on Black African ethnicity who died, around two-thirds of whom were new immigrants, asylum seekers or refugees. Several deaths in Asian women occurred amongst newly-arrived brides who could not speak English and with late booking common. There were also several maternal deaths amongst women newly arrived from the A8 accession countries. In all 26 women who died from maternal causes, another 4 who died from coincidental causes, and two who died some months after childbirth spoke little or no English. A lack of suitable interpreters was a key finding of the enquiry. Late booking and poor attendance for care can contribute to poor birth outcomes. NICE's most recent high level grade evidence review on pregnancy and complex social factors reported that pregnant women of minority migrant or black and minority ethnic origin appeared to be at increased risk of severe morbidity compared with white British women and that recent evidence supported current recommendations to provide interpreter services⁴⁷.

The following examples of good/promising practice have been cited: <u>South Staffordshire PCT</u> <u>maternal care pathway</u>: a project team of midwives from Staffordshire and Burton hospitals have developed a maternity care pathway for non-English speaking women, outlining how language needs

⁴⁴ Cooke G, Hargreaves S, Natkunarajah J, Sandhu1 G, Dhasmana D, Eliahoo J, Holmes A, Friedland JS. Impact on and use of an inner-city London Infectious Diseases Department by international migrants: a questionnaire survey. *BMC Health Services Research* 2007; 7: 113.

⁴⁵ White VL, Paliwalla M, Steves CJ, Jadhav D, Moore-Gillon J: Management of tuberculosis in a British innercity population. *J Public Health Med* 2002, 24:49-52.

⁴⁶ Centre for Maternal and Child Enquiries. Saving Mothers' Lives. Reviewing maternal deaths to make motherhood safer: 2006-2008. *British Journal of Obstetrics and Gynaecology* 2011 (March); vol 118, supplement 1.

⁴⁷ NICE. *NHS Evidence. Pregnancy and Complex Social Factors. Evidence Update January 2012.* Accessed at: http://www.eguidelines.co.uk/eguidelinesmain/gip/news/news_mar12.php#art2

should be identified at registration then passed on to professionals throughout the antenatal, intrapartum, and postnatal care⁴⁸. <u>Bilingual Maternity Support Workers (BMSW)</u>, <u>London Borough of Hackney</u> were established as part of a multi-disciplinary and multi-intervention project to reduce infant mortality in Hackney from 2007-2009. The BMSW role was created to support women who encountered difficulties engaging with maternity services because English was not their first language⁴⁹. **Grade [both G4]**

Summary: Elements of good practice in service models

Research studies have indicated that asylum seekers and refugees experience significant difficulties in trying to register in mainstream practices. Feldman (2008), for example, referred to 'obstructive and sometimes explicitly hostile attempts by practice staff to avoid registering clients which, in some cases could be described as discriminatory'. Sometimes the problems were due to administrative procedures and a widespread reluctance to use interpreters.

There are several models of good practice to achieve GP registration:

- i. The use of health advocacy workers for refugees and asylum seekers can help navigate barriers to registration and achieve significant numbers of new registrations.
- ii. Specialist practices for asylum seekers and refugees undoubtedly ease registration, for example, Feldman (2008) notes that: 'The health advocates initially accompanied or referred patients to the Oasis practice [this was a specialist practice in Hounslow that closed in 2007] where it was very easy for them to get registered. It was more difficult if the client lived far outside Oasis' catchment area, and became generally more difficult after Oasis closed'.
- iii. In the absence of specialist practices, local enhanced schemes that incentivise GP registration of asylum seekers and refugees may be an effective alternative though no evaluations have been identified.
- iv. An innovative approach (adopted by Sheffield PCT) is to bus new arrivals in induction centres to specialist and other GP practices for registration and initial assessment.
- v. New entrant schemes also facilitate GP registration and initial assessment.

⁴⁸ For further details see:

http://www.maternityaction.org.uk/sitebuildercontent/sitebuilderfiles/guidancecommissioninghealthservvulnmig rantwomen2012.pdf (p. 52).

⁴⁹ For a report of interim findings see: http://www.teamhackney.org/reducing_infant_mortality_in_hackney_-_interim_report_october_2008l.pdf

With respect to wider utilisation of GP services, there has been much debate about the advantages and disadvantages of the specialist vs. mainstream model⁵⁰.

The mainstream model with or without supplementary provision

<u>Advantages</u>

- All practices gain experience from having asylum seekers and refugees as their patients
- When registered with mainstream practices, the impact of fluctuations in the size of the migrant population is spread
- If the migrant population is widely dispersed geographically or small in numbers, mainstream practices may be a more cost-effective option
- Feasibility can be added to the mainstream service model by having dedicated additional services outside scheduled clinical sessions, run jointly with other practices if needed and linked to refugee community organisations

Disadvantages

- Mainstream practices may not find it affordable to provide practice-based specialist services
- Staff in mainstream practices may not be as sensitive to vulnerable migrants' needs as staff in specialist practices

The specialist model

Advantages

- This service model alleviates the problem of registering asylum seekers with mainstream GP practices.
- It thereby relieves pressure on mainstream practices of large numbers of asylum seekers, refugees, and other migrants
- Avoids risk of temporary registration by mainstream practices
- Assists vulnerable persons who experience most access barriers and offers those with complex needs more services
- Staff have specialist interest and knowledge of issues that are particular to asylum seekers and refugees

⁵⁰ See, for example, discussions in R Feldman. Primary health care for refugees and asylum seekers: a review of the literature and a framework for services. *Public Health* 2006; 120: 809-816; R Feldman. Guidance for Commissioning Health Services for Vulnerable Migrant Women. London: Maternity Action & Women's Health and Equality Consortium, 2012 (February); and J Eling. Asylum seeker, refugee and vulnerable migrant services: mapping and best practice report and recommendations. Available at http://www.maternityaction.org.uk/commissioning_guidance.html.

- Such practices typically offer holistic multi-disciplinary service and are adequately resourced in terms of appointment times;
- They are able to conduct thorough initial assessments & have good interpreting arrangements
- Staff have knowledge/interest/empathy for vulnerable migrants. Greater knowledge of other services to which migrant patients can be referred, and offer better continuity of care

Disadvantages

- Practices may be penalised in QOF (Quality & Outcomes Framework) remuneration because they cannot meet the standard targets, though some (former) PCTs have developed specific QOFs.
- Some specialist practices provide time-limited services, requiring the eventual passing on of patients to mainstream services.
- Another concern is that separate services may marginalise refugees.
- Mainstream practices do not gain knowledge about migrant populations which may sustain prejudice.
- There has also been debate over whether specialist practices that serve vulnerable population groups simultaneously (e.g. asylum seekers and homeless people) cater to the needs of either group adequately.

Implications for further research/evaluation

- 1. The Health Protection Agency (HPA) has called for a targeted approach to identify the migrants least likely to register for healthcare notably, asylum seekers and refugees but also students and to promote access among both migrant groups and GPs and other healthcare providers through increasing awareness of eligibility for primary care. Research is needed to assess the efficacy of new entrant *cohort* approaches to targeting, including capture of newly dispersed asylum seekers, versus the area-based capture of heterogeneous vulnerable migrants within specific populations (e.g. those populations for which Clinical Commissioning Groups have responsibility) to achieve higher GP registration rates.
- 2. Research/evaluation studies are needed to assess interventions to increase awareness of eligibility for primary and secondary care among i) GPs and secondary healthcare staff (through, for example, HPA and other guidelines, information, and resources) & ii) vulnerable migrants (through, as the HPA has suggested, publicity surrounding welcome health checks or the issuing of lists of GP practices by local councils, employers, or with visas): the impact of such interventions could be assessed through trials or prospective cohort studies.

- 3. Research is needed to identify what initiates GP registration amongst new entrants and when registration takes place after entry to better understand why high proportions of new migrants do not access primary care services.
- 4. A range of specific organisational interventions have attempted to increase registration with and access to GPs and to provide new entrant health screening. Research/evaluation studies are needed to assess how successful these community-based interventions are, with respect, for example, to the range of migrants entering the country (asylum seekers [including failed asylum seekers], students, family reunion migrants, migrants here on a work permit, undocumented/irregular migrants, etc.), the extent of provision of formal screening/expanded new patient checks for new arrivals, vaccination, referral for formal TB screening, etc. A range of service models have been operationalized, all of which require formal evaluation.

3.2 Gypsies and Irish Travellers

Definition

In this report the terms 'Gypsies/Travellers', 'Gypsies and Travellers', and the Census term 'Gypsy or Irish Traveller' have been used in a generic sense to encompass Gypsies, Travellers, and Roma, though clearly recognising that these three groups do not constitute a homogeneous collectivity. The terms may cover English and Welsh Gypsies, Irish and Scottish Travellers, and Roma from Eastern and Central Europe (including recent migrants). In turn 'Roma' may encompass many different groups which may have geographical/territorial associations and are ascribed and/or self-ascribed, such as Vlach Rom, Rom, Kalderash, Manouche, Sinti, Tattare, Kaale, Cale, Lavari, Ursari, Boyhas, and Luri. However, the report does not explicitly address interventions that focus on New (Age) Travellers, bargees or boat dwellers (occupational boat people), circus people, and showmen (fairground people). The Department for Children, Schools and Families provides a useful report on the heterogeneity of these groups⁵¹.

3.2.1 Policies on Gypsies/Travellers

The Coalition Government set up a dedicated Ministerial Working Group (MWG) in November 2011 to drive action across Government to help improve the life chances of Gypsy and Traveller communities. In April 2012 the MWG published a progress report which included 28 commitments from across Government (and 'for which the Government will be held to account') that would help mainstream services work more effectively with these communities⁵². These areas included identifying ways to improve health outcomes for Gypsies and Travellers within the new NHS structures, though oddly made no reference to the preceding Panel Review evidence⁵³. Reflecting devolved responsibilities, the report only covered England with respect to health policies.

The report highlighted generic commitments, such as the duty of the NHS Commissioning Board and clinical commissioning groups to have regard to the need to reduce health inequalities in access to and the outcomes from healthcare, but specific commitments were few, aspirational, and downstream with respect to the National Inclusion Health Board work programmes: that 'DH will work with the National Inclusion Health Board and the NHS, local government and others to identify what more must be done to include the needs of Gypsies and Travellers in the commissioning of health services; ... will explore how health and wellbeing boards can be supported to ensure that the needs of Gypsies and Travellers with the worst health outcomes are better reflected in Joint Strategic Needs

⁵¹ Department for Children, Schools, and Families. *Gypsy, Roma and Traveller communities – further* information. London: DCSF, 2010. Accessed at: http://www.school-

portal.co.uk/GroupDownloadFile.asp?GroupId=922199&ResourceId=3161888 ⁵² Communities and Local Government. *Progress report by the ministerial working group on tackling* inequalities experienced by Gypsies and Travellers. London: DCLG, 2012 (April).

⁵³ See: http://www.edf.org.uk/blog/wp-content/uploads/2011/04/A-Big-or-Divided-Society.pdf

Assessments and joint health and wellbeing strategies; ...will work with the UCL Institute of Health Equity and the Inclusion Health working groups to identify gaps in data and research, and look to identify the specific interventions that produce positive health outcomes; ... will work with the Inclusion Health working groups to identify what more needs to be done to improve maternal health, reduce infant mortality and increase immunisation rates; and... will work with the National Inclusion Health Board to embed the Inclusion Health programme in training for all health professionals, with the aim of developing a strong, stable and capable workforce that can drive change and make a difference to the lives and health outcomes of the most vulnerable'. Although commenting on the weak evidence base resulting from the absence of national data collection, DH did not use this opportunity to affirm mainstream data collection using Census categories (unlike the prison information system, P-Nomis, and the DWP). Clearly, other commitments (such as those on education, notably, the repeal of section 444 of the Education Act, appropriate accommodation, notably, increased enforcement against unauthorised sites through increasing local authorities' powers to use temporary stop notices, and improving access to employment) in the report impinge on the wider determinants of health.

The main criticism of the mid-2012 stock-taking paper of the Coalition Government's policies on Gypsy/Traveller communities by Ryder, Cemlyn *et al.*⁵⁴ is that their policy framework is hierarchical, does not engage with or adequately promote community groups, and opposes forms of positive action, in contradistinction to the policy ideal of mediation and delivery through community representation and intercultural dialogue to ensure that change is relevant and tailored to the needs of the community. Fears are expressed that the NHS reforms will exert pressure on general practitioners to reduce referrals to secondary hospital care, thereby accentuating tensions and mistrust between Gypsies and Travellers and health staff. Similarly, increased pressures on community nursing services will also have implications for Gypsy/Traveller communities who already experience difficulties in accessing services. Such pressures they argue will ensure that the Primary Care Service Framework for Gypsies and Travellers 'will be increasingly hard to implement'. Further, the report authors express anxieties about the impacts of new reforms on the fate of Pacesetters Programme which aimed to reduce Gypsy, Roma, and Traveller (GRT) health inequalities through innovative approaches. Many of these initiatives appear not to have been sustained as few were embedded in mainstream practice. The Panel Review evidence highlighted the trauma, mental and physical health problems endured by young Gypsies, Roma, and Travellers as a result of inadequate accommodation and experiences of eviction and discrimination, though the inter-ministerial report makes no reference to inter-agency work with young people in this area. Indeed, substantial concern had been expressed in this evidence-taking about the impact of spending cut-backs on a whole range of services, including cross-departmental

⁵⁴ Ryder A, Cemlyn S, Greenfields M, Richardson J, and Van Cleemput P. A Critique of UK Coalition Government Policy on Gypsy, Roma and Traveller Communities. *Accessed at: www.edf.org.uk/blog/wp-content/.../Coalition-Paper-5th-June1.docx*

and inter-agency work for young people and Supporting People services, impacting detrimentally on outreach services on authorized and unauthorized sites.

It is noteworthy that Roma are virtually ignored within the inter-ministerial report's deliberations. This failure has been interpreted as a tiered approach in Government thinking on GRT communities where indigenous Gypsies and Travellers are viewed as having more legitimate concerns and interests than those of the more recently arrived Roma communities (Roma Support Group, 2012). Some consideration is given by Ryder, Cemlyn *et al.* to the impact of accommodation circumstances on health. Residents of unauthorised sites experience problems accessing health and education services and the instability of their accommodation impacts negatively on life chances, the support to healthy lifestyles of suitable accommodation being evidenced in numerous health studies. However, a dramatic shortfall in ongoing pitch provision continues to be a key issue and the effect of returning decision making on sites to local authorities – thereby fitting in with the aim of 'empowering' communities under the Localism Act 2011 – remains unknown. Moreover, no clear cut examples of such good practice are within the report which Ryder, Cemlyn *et al.* '...consider to be a wasted opportunity given the breadth of readership'.

They retain their strongest criticism for the lack of meaningful engagement: 'British GRT groups, (which include a number of individuals actively engaged in European policy development) were outraged at their exclusion from the work of the UK inter-ministerial committee on Gypsies and Travellers and the decision by the Coalition Government not to submit a formal NRIS to the Roma Framework. In response a number of activists and GRT led agencies are forming autonomous policy hubs to work on accommodation, education, health and employment fields: the key action areas to be included within the Roma Framework'. They make a plea for the MWG '...to be more direct and proactive in its support for the fledgling GRT third sector rather than leaving it to agencies such as the small national charity Travellers Aid Trust who have been at the forefront of promoting skills development and 'set-up' support for GRT community groups'.

While acknowledging difficulties in accessing primary care, no immediate remedies were offered by the MWG. However, as acknowledged by Ryder, Cemlyn *et al.*, there remains in place the attempt to address this issue in 2009 through the publication of a primary care service framework. NHS Primary Care Contracting issued the Primary Care Service Framework for Gypsy and Traveller communities on 19 May 2009⁵⁵. This top down provision of infrastructure identified a number of elements of best practice:

⁵⁵ NHS Primary Care Contracting. *Primary Care Service Framework: Gypsy and Traveller Communities*. 19 May 2009. See:

http://webarchive.nationalarchives.gov.uk/20090703135533/http://pcc.nhs.uk/uploads/primary_care_service_fra meworks/2009/ehrg_gypsies_and_travellers_pcsf_190509.pdf

- PCT to have a named senior manager lead for Gypsy/Traveller health; partnership working with local authorities; improving cultural awareness and competence on the part of health service providers; proper needs assessments for the community; better coverage of Gypsies and Travellers in NHS monitoring; use of a special flag to identify Gypsy & Traveller records
- Partnership working with Gypsy /Traveller communities in the delivery of healthcare; the need to build trust and understanding with the community; effective engagement with community members; additional outreach preventive services and mobile public health campaigns where appropriate; commissioning dedicated or specialist health workers (including community development & liaison role); ensuring access to appropriate advocacy services; practice-based outreach worker/advocate to visit sites regularly; effective signposting into mainstream services by advocates; properly resourced involvement of Gypsies & Travellers in designing and developing new services and in the review of services
- Achieving stability and continuity of services; offering of full rather than temporary registration where possible; fast-tracking of Gypsies and Travellers into mainstream primary care services given their mobility and regular review of care pathways; hand-held records, including preparation of portable summary records, or family-held records; use of SMS text messaging software to send reminders about appointments; provision of walk-in appointments; acceding to requests to see other family members in the consulting room; and provision of longer consultations (up to 20 minutes)

The framework document states: 'This PCSF is not about providing different or separate services for Gypsies and Travellers; rather, it is about ensuring that these communities can access the same high quality, mainstream primary care services as everyone else. It may be used to assist PCTs to design new services where none exist or to adapt or frontend existing ones to make them accessible to these groups'. While there has been no formal evaluation of the impact of this framework, most commentators have been critical on the grounds of its optionality and lack of a tie in to resources.

While central government is the key player in devising policies for the Gypsy and Traveller communities, it is not the only one. The Equality and Human Rights Commission has been influential in producing the evidence base needed for policy⁵⁶ and also in focusing on key human rights issues, such as inequalities in relation to accommodation, including limited pitch provision, and their relationship to health⁵⁷. Its 2012 Human Rights Review⁵⁸ found that, with respect to the right to a

⁵⁶ See, for example, Cemlyn S, Greenfields M, Burnett S, Matthews Z, & Whitwell C. *Inequalities experienced by Gypsy and Traveller communities: a review*. Research report 12. Manchester: Equality and Human Rights Commission, 2009.

⁵⁷ See: EHRC. Equality and Human Rights Commission policy report. *Submission to the United Nations Committee on the Elimination of all Forms of Racial Discrimination on the UK's* 18th, 19th and 20th periodic reports. London: EHRC, 2011 (July). Accessed at:

http://www.equalityhumanrights.com/uploaded_files/humanrights/cerd.pdf

home protected by Article 8, the rights of Gypsies and Travellers were sometimes overlooked, the lack of sufficient sites making it difficult for these communities to practice their traditional way of life. The eviction at Dale Farm, Essex, may be seen to challenge these rights to a home, raising such issues as where responsibility lies in the case of finding those evicted somewhere to live. Gypsy/Traveller organisations have expressed health and safety concerns about the state of such sites following eviction.

Finally, Gypsy, Roma, and Traveller organisations are becoming increasingly proactive in seeking effective health and social care policies for their communities. They are achieving this through undertaking or commissioning research studies, publishing policy papers and guidance, lobbying activities (for example, with members of the House of Commons and House of Lords) to table questions), submitting evidence to official enquiries, and through representing their communities on bodies such as the National Inclusion Health Board and its working groups.

As the 2012 report of the Scottish Parliament's Equal Opportunities Committee on Gypsy/Travellers and Care clearly demonstrated, the difficulties Gypsies and Travellers experience in accessing services (particularly uncertainty over GP provision) and their poor health status (including disturbingly low life expectancy and chronic ill health in late adulthood) have been enduring challenges over many years and that policies have had little lasting impact: 'We are frustrated by the fact that, despite various reports and initiatives since devolution – which themselves followed on from previous initiatives under the Scottish Office – very little has been achieved to improve the lives of Gypsy/Travellers. In fact, Gypsy/Travellers still face many of the same problems that have troubled them for decades'⁵⁹. This gloomy prognosis suggests that radical changes are needed that, at a minimum, require fresh thinking on issues such as access to primary care and also the mainstreaming of effective service interventions which at present are often abandoned on the expiry of grant-aided funding.

3.2.1 Access to primary care

Access to primary care has been a key focus in the provision of healthcare to Gypsies/ Irish Travellers. GP registration rates are variable and frequently low. The major study by Parry, Van Cleemput *et al.* (2004) found that of their sample of 293 Gypsies/Travellers only 84% were registered

⁵⁸ Equality and Human Rights Commission. *Human Rights Review 2012. How fair is Britain? An assessment of how well public authorities protect human rights.* Manchester: EHRC, 2012 (March).

⁵⁹ The Scottish Parliament. *Equal Opportunities Committee*. 3rd Report, 2012 (Session 4) Gypsy/Travellers and Care. Edinburgh: The Scottish Parliament, 24 September 2012. Accessed at:

 $http://www.scottish.parliament.uk/S4_EqualOpportunitiesCommittee/Reports/eor-12-03w-rev2.pdf$

with a GP and fewer (79%) had seen a GP in the last year⁶⁰. 16% were not registered with a GP either where they were living or elsewhere. Only one of the comparator group (n=260) was not registered. In addition 6 of the Gypsy/Traveller sample were unsure and a further 9 only had temporary registration. Travellers living on sites or in housing were most likely to be registered with a GP. Of those living in trailers on empty land 38% were not registered and of those who travel all year 37% were not registered. By contrast, the All Ireland Traveller Health Study showed that 93.9% of Travellers in Northern Ireland (n=1,424) (asked only in NI) were registered with a GP (100% for those aged 65+)⁶¹. Around half of those not registered gave 'recently moved' as the reason.

Rates in England and Wales are highly variable. Fig. 1 provides data from 23 reports that provide information on GP registration. Most rates varied between 80-100% but some are well below this level.



Fig. 1. GP registration rates reported in studies of Gypsy/Traveller health in England & Wales

Key: 1: 1988, 85%; 2: 1989, 96%; 3: 1989, 56%; 4: 1995, 91%; 5: 1999, 86%; 6: 2001, 49%; 7: 2002, 50%; 8: 2005, 91%; 9: 2006, 91%; 10: 2006, 100%; 11: 2006, 80%; 12: 2007, 90%; 13: 2008, 98%; 14: 2008, 92%; 15: 2008, 38%; 16: 2008, 37%; 17: 2008, 50%; 18: 2009, 86%; 19: 2009, 94%; 20: 2010, 93%; 21: 2010, 84%; 22: 2011, 67%.

⁶⁰ Parry G, Van Cleemput P, Peters J, Moore J, Walters S, Thomas K, & Cooper C. *The Health Status of Gypsies and Travellers in England. Report of Department of Department of Health Inequalities in Health Research Initiative*. Sheffield: School of Health and Related Research, 2004 (October).

⁶¹ All Ireland Traveller Health Study Team. *All Ireland Traveller Health Study. Our Geels. Technical Report 1. Health Survey Findings.* Dublin: School of Public Health, Physiotherapy and Population Science, University College Dublin, 2010 (September).

Selected examples:

9. 2006. 91%. (Corinne Thomason. Here to stay. An exploratory study into the needs and preferences of Gypsy/Traveller communities in Cheshire, Halton & Warrington. Chester: Cheshire, Halton & Warrington Racial Equality Council, 2006 (July). Registered with a doctor (n=85); not registered (n=8); 19 experienced difficulties registering, 74 did not; 38 registered with a dentist, 55 not registered with a dentist).

13. 2008. 98%. (Stephen Taylor. *Gypsy Traveller Health & Education Needs Assessment*. London: LB of Bromley, 2008 (August). 44 of 45 interviewees registered with a GP).

18. 2009. 86%. (Twiselton I, Huntington F. *Health Needs Assessment: Cumbria Gypsy Travellers*. NHS Cumbria, 2009 (November). 86% of Travellers in Cumbria are registered with a GP; over half of the Traveller sample was unwilling to identify themselves as Travellers to their GP because of fear of discrimination and negative stereotyping. Sample size: 103. Most of those not registered were living on unauthorised encampments for short periods.

20. 2010. 93%. (*Joint Strategic Needs Assessment: Cambridgeshire Travellers 2010.* 2009 East of England lifestyle survey reported that of 189 Gypsies & Travellers interviewed, 93% were currently registered with a GP, 84% had visited a GP within the last 2 years, and 43% had visited the hospital).

23. 2012. 81%. (Margaret Greenfields. *Meeting the Health Care Needs of the UK Travelling Population*. IDRICS, Buckinghamshire New University. 22 of 27 respondents in Bucks registered with a GP; 16 of 27 reported to be registered with a dentist, 11 of whom with an NHS dentist).

Studies have reported the following findings with respect to Gypsies/Irish Travellers access to and use of GP services:

- Tendency to attend GP surgeries without a pre-booked appointment
- Need to see the GP on the day of presentation
- Reluctance to fill in registration forms
- Reluctance to have information about them collected on file
- Wish to use the consultation for GP for extra consultations with co-present family members including children
- Accorded temporary resident status rather than as fully registered patients through concern about target payments and QOF points
- GP concern about past medical record, provenance of previous diagnoses, appropriateness of declared medication, need for repeat tests and investigations
- Lack of reliability in maintaining their vaccination status, cervical cytology, and screening and monitoring of chronic conditions
- Response to written invitations poor because of literacy problems
- Mobile lifestyle of Travellers making contact difficult
- Late presentation with cancer
- Excess premature death, excess mental health and alcohol-related problems

3.2.3 Interventions: introduction

A wide range of interventions have been introduced on a piecemeal basis. Systematic programmes of interventions with respect to implementation and/or evaluation include the Pacesetters Programme⁶², and the Roma SOURCE/European Union Fundamental Rights and Citizenship Programme projects. Two of the 2012 awards for Inclusion Health Scrutiny Development Areas are focusing on Gypsies/Travellers (via the Centre for Public Scrutiny (CfPS⁶³)): South Somerset is looking at maternal health within the Gypsy and Traveller community. The CfPS model is providing structure for the review and the committee is preparing impact statements looking at maternal wellbeing and antenatal care in relation to wider determinants such as housing, access, etc., maternity/delivery pathways, and synthesising the substantial body of evidence on poor birth outcomes and post-natal care. The committee is also planning to establish links with the local Gypsy and Traveller Liaison group to look at how to best communicate with the community in a sensitive and appropriate way and to explore the role of scrutiny within a district council and how it might link with the county; Southwark is conducting a review into health inequalities within Gypsy and Traveller communities. The intention is to build collaborative relationships with stakeholders and to gain insight by holding networking and stakeholder events. Their approach to stakeholders will be tailored to suit the specific needs to the local Gypsy and Traveller populations to help create better relationships and avoid replication of barriers and exclusions. Initial findings of the scrutiny reviews are reported in section 3.2.5.

Many Gypsy/Irish Traveller organisations pilot new interventions related to access to primary care, for example, or provide guidance and literature on good practice⁶⁴. Much of their day-to-day work may impact very beneficially on the lives of individual Gypsies/Irish Travellers but not fit neatly into generic service models⁶⁵.

 ⁶² Van Cleemput P, Bissell P, Harris J. *Pacesetters Programme. Gypsy, Roma and Traveller core strand. Evaluation Report for the Department of Health.* Sheffield: ScHARR, The University of Sheffield, 2010 (April).
 ⁶³ See: http://www.cfps.org.uk/forum/showthread.php?tid=1025

⁶⁴ See, for example, ITMB's Health and Wellbeing Project, including work undertaken in partnership with the Royal Free Hospital, which was awarded the All Party Parliament group in Maternity Care award (ITMB. Maternity Care & Irish Travellers: A guide for NHS staff & Irish Travellers. DVD.); Mental Health & Wellbeing Project (Tell Someone. DVD) Friends, Families & Travellers's Food & Mood: how to feel better & eat well; Eat well; The Sussex Traveller Women's Health Project Recipe Book; (with South Downs Health NHS Trust), How to keep your smile (quick tips for healthy teeth); DVD: sleeping problems, bi polar,

antidepressants, eating problems, post-traumatic stress disorder, baby blues, depression, self-harm. ⁶⁵ I am grateful to Helen Jones (Leeds) and Rose Palmer (Royal Borough of Kensington & Chelsea) for examples.

3.2.4 Interventions to improve generic health awareness and to improve access to primary care

Health Champion Pilot, Sheffield

The Sheffield Health Champion pilot is one of three health champion pilot projects run and funded through the EU Roma SOURCE project, including Bradford and Rotherham. It was led by NHS Sheffield, in collaboration with Sheffield Wellbeing Consortium and the Pakistan Advice and Community Association (PACA). This initiative was adopted as top-down approaches to Roma health had been shown to be less effective than anticipated. It aimed to encourage healthier lifestyles amongst Sheffield's Roma communities by the use of health champions, '…people from within the Roma community who by example and encouragement could promote a community-led approach to health improvement'.

The aim of the project was to involve Roma people in promoting healthier lifestyles within their own communities. The elements of service provision encompassed: *health champions* – the project trained up two Roma volunteers from the local community as 'lead health champions' who received detailed training through Sheffield NHS and Altogether Better. In turn they trained other Roma as 'supporting health champions', the full group of champions including both men and women. The champions helped to run and organise a number of sessions for local Roma. *Zumba classes*: Given the widespread enthusiasm for dancing within the local Roma community, the health champions set up Zumba classes combining dance and aerobic elements for Roma people as a means of providing enjoyable exercise. There was extensive take-up, with separate male and female classes. *Healthy eating:* The champions ran a men's lunch club for the Roma which provided one-to-one dietary guidance and support and developed posters on healthy eating in the Roma language to make the message accessible. *Football*: The health champions set up 'Spartak Slovak', a Roma football team now taking part in the national 'Integration through Football' league.

Reported elements of best or promising practice encompass: *inclusion* - using Roma people to work within their own community, to set their own priorities for health improvement, and raise awareness of health issues within Sheffield's Roma community ensured community involvement in the pilot; *partnership* – involving the public sector voluntary organisations, and community members, each contributing to the success of the project; *personal development* – the two lead health champions subsequently gained salaried employment in health-related areas on the strength of the skills acquired in the project; *community engagement* – the project built on work undertaken within the Roma community by PACA; members of the Roma community have been encouraged to take a more active part in community voluntary work (which has continued after the end of the project). **Grade [G1, IE]**

The 'Health Ambassadors' Programme

Three NHS Trusts in the East Midlands SHA contributed their resources to deliver the 'Health Ambassadors' programme. A total of thirty Gypsy/Traveller community members were trained as health ambassadors to raise awareness of the culture and health needs of Gypsy and Traveller communities, to break down barriers, and encourage trust and dialogue with healthcare staff. At the time of the evaluation, the 'Health Ambassadors' had delivered over sixty training sessions to around 800 staff from various disciplines across the East Midlands region. According to the evaluation by Van Cleemput *et al.*, staff evaluations were positive, confirming achievement of the aims of the intervention. Changes to staff practice that were identified included improved communication skills resulting from improved awareness and understanding and practical changes like texting reminders for appointments. In one of a few GP practices where training was delivered, Gypsy/Traveller community members were more prepared to attend as a result of the intervention. 'Health Ambassadors' showed increased confidence in communicating with health staff, including an increased willingness to ask questions about their care and treatment. At the time of the evaluation there were plans to sustain the work, a waiting list of additional Health Ambassadors wishing to be trained, and current Health Ambassadors wanting to further develop their role. **Grade [G1, IE]**

Community health advocates

The Wellbeing for Travellers scheme⁶⁶, led by NHS Buckinghamshire's Mental Health Community Development Team, was launched in June 2009. It is a project which improves health for Travellers and Gypsies by training young women in the Gypsy/Traveller community to become community health advocates for their friends and families. In 2010 it was anticipated that the project would benefit 60 families in Buckinghamshire and offer the potential to be used as a model for similar projects across the UK. NHS Buckinghamshire indicated that the project was one of the first in the country to overcome barriers to training, such as little or no literacy skills, and to engage with and teach health and social care skills to the Gypsy/Traveller community.

The advocates have been trained to pass on first aid skills, deliver advice and information about health services and screening programmes (such as cardiovascular and cancer), and to promote healthy lifestyles. Around a year into the scheme, it was stated to be playing a crucial role in improving the health of those living on Gypsy and Traveller sites. The recently trained health advocates have been working with the Health Protection Agency to devise ways of passing on information and advice to

⁶⁶ This project was overall winner in the 'Success in Partnership Working' programme at the regional Health and Social Care Awards.

local Gypsy/Traveller communities to protect children and families affected by common infections and diseases. The scheme is the result of a partnership between NHS Buckinghamshire, Buckinghamshire New University, One Voice 4 Travellers Ltd and Uni (South East BME) Network, and has been supported by the Buckinghamshire Community Foundation. No formal evaluation is available⁶⁷. **Grade [G4]**

Cultural awareness raising projects

Two additional Pacesetter Programme projects have addressed staff cultural awareness training. In the South West SHA projects encompassed staff cultural awareness raising and a directory of local services for the Gypsy/Traveller community. The project began with a synthesis by NHS Bristol of all Gypsy and Traveller work across the Greater Bristol sub-region. Staff awareness training regarding culture and health needs resulted in a two-stage project with five Gypsy/Traveller community members recruited by a peer community development worker to a 'Confident to Present' training course. At the time of the 2010 evaluation by Cleemput *et al.*, initial staff training sessions to be delivered by the community educators were planned. The second component of the South West SHA projects, a directory of resources, was produced in consultation with community members and through multi-agency collaboration. The aim of the directory is to increase awareness of local services, support access to health care, and to serve as a health promotion tool. The evaluation reported that the distribution of the directory was in progress. The continued involvement of the community development worker and health visitor will facilitate the review and update of the directory and provision of further staff training sessions. **Grade [G1, IE]**

A second Pacesetter Programme project, in Yorkshire and Humber SHA, has focused on raising awareness among Gypsy/Traveller communities and staff cultural awareness raising. Activities to increase community participation and health awareness resulted in the commissioning of an 'Introduction to Community Development and Health' course in order to support Gypsy/Traveller community members to further develop their skills and become active within their community on health projects. A core group of 4-5 community members attended the first term but interest was not sustained. One of the lessons learned was that more time was needed and that developing capacity in a divided community required additional resources, including a regional approach involving other established community support agencies. A celebration event was held with invited speakers from neighbouring Gypsy/Traveller communities, including Health Ambassadors from East Midlands, to heighten awareness of opportunities for personal development.

⁶⁷ A report on the project appears in the *Travellers' Times* of 31 March 2010: 'Women of well-being'. See: http://www.travellerstimes.org.uk/list.aspx?c=00619ef1-21e2-40aa-8d5e-f7c38586d32f&n=5315cea4-f61c-4930-8db2-3a92f8fe0c0d

A neighbouring community members association was also commissioned to deliver staff awareness sessions: 55 staff from various agencies attended the three sessions. According to the evaluation by Cleemput *et al*, the input from community members had the most immediate impact on participants and most gave favourable evaluations of the training. **Grade [G1, IE]**

Increasing GP registration projects

The NHS Newham Pacesetters project⁶⁸ was established to address the health needs of the Roma community in Newham, estimated at around 900 families. The main objective of the project was to increase registrations with GPs, with additional aims to work to improve the Roma community's awareness of health issues and build confidence within NHS Newham in dealing with Roma people. The scheme was delivered through a partnership between NHS Newham and Roma Support Group (RSG), a voluntary sector organisation working to improve the quality of life of Roma people. The project brought together a range of professionals from across clinical, acute care, mental health, education, and other backgrounds to work towards better health outcomes for Newham's Roma. The service provision encompassed a number of elements to engage Roma people: a Roma health communication worker was employed for two days a week and was based within the Roma Support Group, a central access point within the Roma community, to offer individual help to people regarding health issues and to conduct interviews to assess health needs; a cultural awareness programme involving training sessions carried out amongst NHS Newham staff by Roma Support Group to raise awareness of the culture, tradition and health needs of Roma people, including age and gender issues and to build confidence in dealing with them; a *health event and health MOT* held at the end of 2009 in conjunction with the RSG's AGM, highlighting issues around smoking, diet and heart disease and offering attendees a health MOT (measuring BMI, blood pressure, and blood sugar levels); and transitional terms of registration to enable Roma people to register with a GP with a proof of ID rather than a proof of residence ('to take into account the fact that many Roma are overseas nationals and in housing situations that make producing proof of residence difficult'), so providing a direct means of addressing low levels of GP registration.

Elements of promising practice encompassed: the focus (an opportunity for mainstream health providers to identify and address health issues within the Roma community); partnership between NHS Newham & RSG, central to the project's success as RSG are trusted by the Roma community and therefore facilitated access and engagement; professional development, the building of the

⁶⁸ This was also a Roma Source (Sharing of Understanding Rights and Citizenship in Europe) project, co-funded by the European Rights and Citizenship Programme. See: Roma SOURCE and European Union's Fundamental Rights and Citizenship Programme. *Improving the health of Roma communities in the Yorkshire and Humber Region. A guide to good practice.* Leeds: Migration Yorkshire (for the Roma SOURCE project), 2012.

knowledge and understanding of NHS staff to address the particular needs of the Roma community effectively being an essential element of the project; and innovation (the involvement of the RSG enabling discussion of taboo health issues such as mental health). **Grade [G1, IE]**

Health trainer projects

A number of these projects have been described in the wider evidence base but few evaluations are available. They have been funded by a number of different funding streams, including the National NHS Health Trainers Programme (HTP), HEFCE (Higher Education Funding Council for England)'s South East Coastal Communities (SECC) Project, and local area funding streams.

In the National NHS Health Trainer Programme, only one (<1%) of the 131 Health Trainer Services (HTSs) focuses on Gypsies/Irish Travellers: in Barnsley £336,000 of mainstream PCT funding was secured to deliver the local HTS. The PCT commissioned the service from 5 different voluntary and community organisations (VCOs), one of which is the Barnsley Black and Ethnic Minority Initiative (BBEMI). There are 16 health trainers in total, 14 based in 4 deprived parts of the district and 2 with Gypsies and Travellers. 3 to 4 health trainers work as part of a small community development team, and are managed by the community development worker in each locality, plus 2 work with Barnsley Black and Minority Ethnic Initiative (BBEMI). The health trainers, most of whom started out as community volunteers, do a lot of outreach, much as part of activities organised by the community development team. The health trainers aim to see clients for 6 sessions (but are flexible according to need) in their homes or a variety of accessible settings. They work with clients on whatever issue is a priority to them and can accompany clients to services/activities where needed. A major part of their role is to reconnect clients who have lost trust in professionals, into services such as dentists and GPs, and to signpost to other services (e.g. for food boxes for those without the means to pay). Health trainers have negotiated free entry to the local leisure centre where they are accompanying a client. If several clients are expressing a need for an activity or service, this is referred to the CD team who, if there is sufficient interest, will work with local people to set up local activities in response to need. Health trainers work closely with the Stop Smoking Service (SSS), doing home visits for clients unlikely to make it to the SSS in Barnsley: 39% of the primary issues which clients in Barnsley decide to work on are smoking. The health trainers are also trained to take blood pressure.

The role of Rayner Morrison as a paid health trainer with the Gypsy and Traveller community in Barnsley has been documented⁶⁹. As a native of Barnsley, member of this community, and part of the caravan dwelling population, Rayner met a public health manager at the PCT and with her

⁶⁹ NHS Health Trainers England. Case Study: Working with Gypsy and Traveller Communities in Barnsley. http://www.healthtrainersengland.com/barnslay-case-study.

encouragement and that of the manager of BBEMI applied for and got a job with the health trainer service. She undertook a training programme to qualify as a health trainer and now works with BBEMI to provide the service to the local Gypsy and Traveller community. She helps organise events and activities with and for the community, for example, a women's health event which includes a discussion of mental health issues, and tells people about services and encourages them to access them where needed which can include accompanying people to attend. Many Gypsies and Travellers are not registered with a GP, so have found the Walk In GP Centre in Barnsley of great value as they don't need to be registered or to make an appointment. Rayner also gives one to one support to people who want to make a lifestyle change (such as stopping smoking or taking more exercise), and other tasks like supporting them to register with a GP, sorting out rubbish collection, or obtaining proper toilet facilities. However she has helped one young woman to train as a walk leader and to set up a walking group and persuaded some of the men to go for health check-ups. Many of the women have supported each other to eat more healthily and lose weight. Rayner is also helping some of the younger people who are literate to apply for places at college. The second health trainer works with Rayner to support the community, connect people into services, and addressing stress and mental health issues. Grade [G3, NIE]

There is little formal evaluation of individual schemes, although a national reporting system provides aggregate information ⁷⁰.

The <u>'Road to Health and Wellbeing'</u> project was funded by the South East Coastal Communities Project (SECC), 2009-11⁷¹. It aimed to provide a preventative health programme which

⁷⁰ The Data Collection Reporting System (DCRS) is a national system funded by the Department of Health (DH) which is used by the majority of health trainer services and enables information about health trainer activity to be collected and reported on at district, regional and national levels. All services using the system have to enter data relating to 4 key outcomes identified by DH and known as the minimum data set. These are: i. increasing capacity and capability through building the workforce with the skills in place to tackle health inequalities; ii. reaching the hard to reach; iii. delivering sustained improvement to the health of the people of England through behavioural change; & iv. providing access to and encouraging the appropriate use and take-up of NHS and other services. In Barnsley health trainers collect information from clients in paper form and enter it into the electronic DCRS when they return to their office base. The system enables managers to identify 'at the push of button' whether they are successfully targeting the clients they want to (postcodes and 'community of interest' is recorded), what issues clients are working on and what progress they have made. For national findings, see: Smith J, Gardner B, Michie S. *Health Trainers. National End of Year Report: 2008-09 (Based on regional end year returns 08/09)*. London: UCL Centre for Outcomes Research and Effectiveness, 2010 (January).

⁷¹ The South East Coastal Communities (SECC) was funded by the Higher Education Funding Council for England (HEFCE) as a demonstrator project from 2008-2011. It involved nine universities in the South East. SECC sought to encourage knowledge exchange between universities and the community across the South East coastal region and was broken down into three locations involving three universities in each area. The aim of the project was for universities to work collaboratively with members of the local community in the area in order to build their capacity to meet their Health and Wellbeing needs.

acknowledged the beliefs of Gypsies and Travellers and which was acceptable and accessible to this community. Canterbury Christ Church University (CCCU) worked in collaboration with the Swale Gypsy Support Group to develop and facilitate the delivery of an innovative, evidence based training programme, provided on a rolling basis over two years to enable Gypsies/Travellers to gain a better understanding of their health problems and ways in which they can more effectively help themselves. It has resulted in the recruitment and development of a total of nine health care trainers from the Gypsy/Traveller community, two of whom have been employed by the NHS.

The project commenced with members of the Gypsy Support Group being trained by the university team to undertake in-depth interviews to ascertain the health beliefs and practices of the Gypsy/Traveller community. Based on the data collected a comprehensive training programme was devised by the Support group which covered topics such as mental health awareness, first aid, and healthy hearts. DVD diaries were produced by the group which contained information about improving and maintaining health and well-being: a key benefit in circulating these to members of the community was seen as their accessibility by those with limited literacy skills.

The SECC project enabled the group to build a strong working relationships with CCCU, to establish important links with other organisations, and to provide a foundation for future work, including the local NHS, South East Coast Ambulance NHS Trust (SECAmb), British Heart Foundation and Rethink.

The South East Coastal Communities (SECC) projects have been evaluated by Step Ahead Research Ltd^{72} . The evaluation of the Swale project indicated that the funding amounted to £148,100, of which £93,000 was provided by SECC, the model now being considered for implementation elsewhere in England. It stated that the project had: '…resulted in a new sustainable community group being established that meets every three months and can work on behalf of the community and engage with public sector organisations, such as the local authorities, Primary Care Trust, and national Government departments. Embedding the project in the local community and using community intermediaries was critical:

"...the gypsy and traveller community (the largest ethnic minority group on the island of Sheppey) had resisted previous approaches by statutory bodies relating to health and remained suspicious of their motives. This had resulted in a number of health problems going unchecked and some potentially harmful misconceptions within the community about how to deal with some conditions. The project consciously took a different track and asked for volunteers to learn about health improvement and become advocates for health and well-being within the community. This is perceived to have been very successful and has attracted national attention within the

⁷² Pratt J, Nairne B, Matthews S. South East Coastal Communities Programme Evaluation: Final Report [Prepared for the University of Chichester & Partner Higher Education Institutions]. Burgess Hill: Step Ahead Research Ltd, 2011 (September).

gypsy community, the health profession and academia as a successful model of delivering public health initiatives in relatively closed communities'.

The project has also resulted in new diversity training modules being delivered as part of teacher training and social science at CCCU. Grade G3 [IE]

In November 2009 NHS Cambridgeshire Community Services announced that it had developed a Gypsy and Traveller health project initiative in response to the increased health needs of this community (which comprises around 1% of the population of the county)⁷³. The team comprises a lead nurse for Gypsy and Traveller health, a project development worker from Cambridgeshire Race Equality and Diversity Service, and advocacy support provided by the Ormiston Children and Families Trust. Additional Local Strategic Partnership Funding from Cambridge City and South Cambridgeshire has been allocated to the project for health trainers to be recruited from within the Gypsy and Traveller community (led by an NHS employed community development worker), to raise awareness of health prevention and promotion. The team: (i) acts as a central resource and champion for queries/concerns related to Gypsy and Traveller health; (ii) develops and delivers appropriate training and awareness raising about Gypsy and Traveller culture, health needs, and barriers to accessing services, to all partner agencies and interested colleagues; (iii) works directly with members of the Gypsy and Traveller community, both on an individual and community basis, to enable them to achieve better health outcomes; and (iv) provides generic advocacy support where needed through the Ormiston Children and Families Trust. No further information has been found on this intervention and no evaluation reports. Grade [G4]

Mobile health and dental clinic projects

A number of mobile health and dental clinic projects were cited as examples of good practice in the 1980s, 1990s and early 2000s. It is likely that these were seen as innovative at the time (and may still be regarded as such in the case of mobile dental clinics) but there has probably been a shift in opinion in the last decade. The emphasis is now placed on securing effective mainstream primary care services for Gypsies and Travellers, the provision of mobile services being seen as a possible barrier to such provision (through displacement). While some mobile clinics continue to be cited as good practice, caution is required in promoting this service model in the absence of robust evaluations.

The Department of Health in 2001 funded the setting up of <u>a pilot scheme to provide Travelling</u> <u>families in Herefordshire</u> with their own personal, GP-led mobile health service. A grant of £900,000

⁷³ NHS Cambridgeshire Community services. Gypsy and Traveller Health Project. Media Release, 10 November 2009.

was allocated to Herefordshire Primary Care Trust to provide the pilot project for three years and it was estimated that 1,200 Travellers will register, the team to comprise a GP, a lead nurse, a practice administrator, and two health visitors. As well as a Travelling families GP surgery, a bus equipped as a mini-health centre will be used like a mobile library, regularly visiting Travelling families wherever they are based. One of the main aims was to improve access to health care as many of the Travellers in the county are reported not to be registered with GPs and some visit A&E departments in Hereford hospitals as a source of primary care. The (former) Commission for Health Improvement's Clinical Governance Review for Herefordshire Primary Care Trust (Commission for Health Improvement [CHI], 2002) states: 'A personal medical services scheme for travelling families is an example of best practice. This scheme was developed with considerable input from the Traveller Community. The trust should continue to develop the patient public involvement programme further and ensure that the patient's voice is heard in policy and planning of services'. The CHI felt this innovation was one of two things in their inspection '...that the rest of the NHS can learn from'. While the service was still active in 2010, there were reports in the Traveller press about difficulties in accessing the service, the ostensible disappearance of the 'special outreach clinics, and non-response from the hotline help number⁷⁴. Grade [G4]

The Leeds health bus was in the past promoted as a good practice example. The bus was used to provide a drop-in service for Gypsies and Travellers. Despite reported restrictions of it being a 'health bus' (the van 'is poorly sound proofed and the consulting room is only 9' by 7"') and extreme difficulties in staffing the bus in a 2005 report, the health bus was seen as an extremely useful service providing high quality care. The perception from health professionals was that it was opportunistic care for a period of two hours a week but could catalyse a long-term relationship with Travellers and Gypsy care in Leeds. One report recorded that in a new venture the health bus visited 'transient' Travellers: 12 women and 15 – 20 children visited the bus. Three men visited to be weighed, the dental oral health promotion co-ordinator gave out toothpaste and brushes to 21 adults and dealt with 4 dental health queries and 4 people had required GP registration for further treatment. A Traveller Link Worker for Social Services and a Mental Health Housing Support team member gave support and advice. The principle of bringing health care to the Travellers site was seen as a good one, but 'the current provision risks perpetuating the provision of inadequate health care. The Gypsies and Travellers need above average service and a health bus does not provide this'. The Leeds health bus service was subsequently closed: 'We campaigned successfully to get rid of it so that local GP

⁷⁴ Service overview, 21 January 2010: <u>http://www.herefordshire.nhs.uk/1034.aspx;</u>

^{&#}x27;Pioneering health project is "falling apart". Travellers' Times 26 August 2009, accessed at: http://www.travellerstimes.org.uk/list.aspx?c=00619ef1-21e2-40aa-8d5e-f7c38586d32f&n=a2474408-98b2-45a2-86f9-cf31ac121383

practices stopped using it as an excuse not to register and provide the holistic GP services to the community there⁷⁵.

In a quick survey of specific health issues in the weeks before the bus visited the site at Spinkwell Lane, Tingley, the services requested included: smoking cessation; dental health – appointments for NHS Dentist; general practitioner for all health matters; nurse prescriber – prescriptions; health visitor re: child health; school nurse – general health for school age children; mental health worker – re depression and stress; and healthy eating advice and dietary needs. Before its closure it was staffed by the health visitor for Travellers, a mental health worker, and the bus driver. There was a two hour drop in clinic once a week on the Cottingley Springs site and a two hour drop in clinic once a week for off-road encampments city-wide with the health visitor and a housing official.

No evaluations have been identified for this intervention. While there are clear benefits with regard to access, the NHS warns of potential drawbacks, notably, that such mobile services may be used as a substitute for effective mainstream services and that a 'ghetto' approach to providing primary care services should be avoided: 'Whilst mobile units can be effective for preventive/screening campaigns, PCTs should note that these are not an effective substitute for properly front-ending or adapting existing mainstream primary care services. Inappropriate use of mobile units can reinforce or even worsen existing prejudices'⁷⁶. **Grade [G4]**

There are a few additional examples. The Irish Government's Department of Health made the necessary funds available to the <u>Eastern Health Board</u> in the mid-1980s to set up a mobile health clinic for the Travelling Community, stating: 'The clinics are on an experimental basis and will provide a number of services but with a particular emphasis on expectant mothers and infants. If the clinic is a success in the Eastern Health Board area the concept will be extended to other areas where there are large numbers of travellers' (Dáil Éireann, 1985). The <u>Northern Area Health Board</u>'s mobile health service for Travellers comprises a mobile clinic providing services to over 40 halting sites and roadside stops four days a week, including a full immunisation service and counselling service for Traveller (Northern Area Health Board, 2002). **Grade [G4]**

The <u>Wrexham Local Health Board mobile unit</u> set up to address the coronary health of Gypsy Travellers has been recently cited as an example of good practice in health improvement⁷⁷. It was set up with £531,000 funding allocated by the Welsh Assembly Government to run from April 2002 to March 2008, the aim being to impact upon the coronary health of Gypsy Travellers and to increase

⁷⁵ Personal communication, Helen Jones, Chief Executive Officer, Leeds Gypsy and Traveller Exchange.
⁷⁶ http://www.pcc-

cic.org.uk/sites/default/files/articles/attachments/ehrg_gypsies_and_travellers_pcsf_190509.pdf

⁷⁷ Welsh Government. *Coronary Heart Disease and Gypsies and Travellers: Redressing the Balance Project.* Cardiff: Welsh Government, 2008 (September). Accessed at:

http://wales.gov.uk/topics/health/improvement/communities/fund/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceproject/?lang=entersection/inequalitiesnorth1/balanceprojection/inequalitiesnorth1/bala

access to primary and secondary care services through an outreach service in a fully equipped mobile unit and outreach Project Health Worker. While initially focusing on Wrexham, the project was subsequently rolled out to Flintshire. A full-time researcher provided a socio-cultural study of the community and an evaluation of the community initiative. The documentation indicates that the community was fully engaged with the project team and felt that they had ownership of the service.

The evaluation indicated that GP registration was offered to all Gypsies and Travellers who participated in the project and that 92% were registered with a GP. **Grade** [G3 IE]

The <u>Bristol Traveller Project</u>, regarded as 'one of the more substantial examples of good practice' in a 2002 SW Public Health Observatory report on Traveller health in the SW Region⁷⁸, includes the successful operation of a mobile dental unit, popular with Gypsy Traveller children, that grew from an identified need at roadside and transit sites used by Gypsy Travellers (EOC, 2003). The project was set up by a health visitor in 1990 and, following a very positive report on the first two years of the project⁷⁹, was further funded by Avon Health Authority. In addition to the mobile dental clinic, initiatives include a Well Woman service with monthly clinics for screening and health promotion and the treatment of chronic problems (though this part of the project ended in the late 90s when Avon Authority declined further funding⁸⁰). In 2003 the <u>South Gloucestershire Travellers Health Project</u> was cited as a good practice example in its provision of a mobile dental clinic for use at festivals, 2-3 days a month (a dentist and dental nurse were hired for such occasions)⁸¹. **Grade [G4]**

Improving the oral health of the Gypsy & Travelling Communities in Sussex

This was one of the few interventions identified that sought to improve the dental health of Gypsies/Travellers (besides the mobile clinics in the preceding section). This programme was funded by *Communities for Health* following a successful bid by Friends, Families and Travellers (FFT)⁸² to Brighton and Hove City Council Public Health Programme. Funding commenced April 2009 for one year to March 2010. The project was developed on the basis of strong anecdotal evidence that Gypsies

 ⁷⁸ Doyal L, Cameron A, Cemlyn S, Nandy S, & Shaw M. *The health of Travellers in the South West region: a review of data sources and a strategy for change*. Bristol: SW Public Health Observatory, 2002 (August).
 ⁷⁹ Neligan D. *Report of a specialist health visitor for Travelling families*. Bristol: United Bristol Heathcare

Trust, 1993.

⁸⁰ Rhodes S. *Travellers Health Project – Women's Health Report*. Unpublished Report for United Bristol Healthcare Trust, 1998.

⁸¹ Devon Health Forum. Travellers Wellbeing. Multi Agency Approaches to Address Issues for Travellers. Accessed at: NHS Primary http://www.devon.gov.uk/travellers_wellbeing.pdf

⁸² FFT is a small national charity that works on behalf of Gypsies and Travellers and runs a health outreach service in Brighton and Hove, East Sussex, and west Sussex in order to help Gypsies and Travellers access mainstream health services. See: FFT. 'A Collaborative Programme to Improve the Oral Health of the Gypsy and Travelling Communities in Sussex'. 2010.

and Travellers suffer very substantial oral and dental health problems which sometimes result in hospital intervention. There is evidence that inequity in dental health and dental service use is greater on unauthorized and transit sites. A service model was developed that utilised a target approach using community advocates as the most effective tool for change. It was delivered via a multidisciplinary team including FFT's strategic health improvement manager, an FFT outreach worker, East Sussex Special Care Dental Service and South Downs Health oral health promotion managers, and West Sussex Community Personal Dental Service's oral health promotion co-ordinator.

A need was identified for cultural awareness training for all members of the dental teams. Basic oral health awareness training was arranged for the FFT team to enable them to promote oral health opportunistically in their contact with the community. Additional oral health promotion training was arranged for the FFT outreach worker who would become the oral health advocate. The specific objectives of the intervention were to improve the oral health of Gypsies/Travellers in Sussex by: providing culturally sensitive oral health awareness training for 8 members of the FFT organisation; train one of their outreach workers as an oral health advocate; design and print simple and appropriate education materials for use by outreach workers; provide visual aids to support the outreach worker; encourage the habit of oral hygiene by provision of oral hygiene packs for outreach; provide cultural awareness for dental teams in Sussex; identify access to dental care across Sussex for Gypsy/Traveller communities; and write up the programme as an example of good practice. A qualitative approach to evaluation was designed with specified outcome measures.

The evaluation revealed that the training sessions for FFT outreach workers had resulted in an increase in oral health knowledge and awareness and that the oral health advocate had acquired the requisite skills. A leaflet in accessible format and visual aid toolkit for use in outreach work were designed. Around 30 oral hygiene packs were distributed and cultural awareness training undertaken for dental teams in Sussex both opportunistically and via a study day. Provision for dental treatment of members of the Gypsy/Traveller community in Brighton and Hove was much improved through awareness raising in the dental teams involved. During the year of the intervention the outreach worker/advocate resulted in information and/or support being provided to 209 community members in Brighton and Hove and 475 people in West Sussex, often through contact with large families. However, sustainability of this process of improvement is fragile due to changes in the commissioning of oral health services in Sussex, financial constraints, and retirement of key staff. A further finding was the need to amend the standard NHS ethnic group classification to capture Gypsies/Irish Travellers in dental care settings. **Grade [G3, NIE]**

GP enhanced service for Gypsies/Travellers: The Market Harborough Practice

Because of the difficulties Gypsies/Travellers experienced in accessing conventional GP care operationalized through the fairly rigid structure of the health service, Market Harborough Medical Centre decided to set up a GP enhanced service for Gypsies/Travellers. This example is cited in the primary care service framework for Gypsy and Traveller communities⁸³ and used in the evidence pack to support Inclusion Health (DH 2010) as evidence of inclusive practice (Cabinet Office 2010).

The enhanced service involves the following changes in practice policy:

- It would have a policy of registering as many Travellers as possible as fully registered patients;
- It would not turn away any Traveller without a consultation or an agreed appointment, even if all appointments were full;
- It would accept any requests to see other family members in the consulting room as an opportunity to improve the screening status of a potentially vulnerable patient;
- It would apply a Read Code to all identified Travellers, whether resident of a site or a house;
- It would use a template for collecting health information on Travellers;
- Having set up medical records for Traveller patients, it would make summary printouts available to those with significant chronic illness to take with them when they went travelling (but taking steps to ensure confidentiality);
- It would appoint and train a practice nurse to visit Traveller sites twice weekly to provide health information and encourage screening, proactive healthcare and full registration [but not to provide actual health care on site];
- It would hold Traveller forums to monitor users' views of the service provided;
- With the gaining of experience, it would provide training to community staff and liaison with local school nurses serving the Traveller community;
- It would not de-register Travellers who travelled away for up to six months;
- Women Travellers who attended would be actively encouraged to persuade their men folk to attend for screening or early diagnosis and treatment;
- Provision of Traveller-friendly leaflets and health promotion literature;
- Male doctors would be prepared to visit sites to encourage older men to attend surgery for screening and early diagnosis.

The cost of the scheme came to around £100 per Traveller in the catchment population (taking into account likely loss of target payments and QOF points; increased staffing to enable elasticity in

⁸³ Care Contracting. Primary Care Service Framework: Gypsy and Traveller communities. 19 May 2009.

http://webarchive.nationalarchives.gov.uk/20090703135533/http://pcc.nhs.uk/uploads/primary_care_service_fra meworks/2009/ehrg_gypsies_and_travellers_pcsf_190509.pdf

appointments; increased doctor hours to enable extra consultations; cost of employing and training a specialist practice nurse undertaking on site sessions; staff and doctor hours expended in planning, administration and communications; and administrative, IT, and stationery costs.

The reported outcomes (as at April 2008) comprised: Increased full registration to around half of the estimated Traveller population in the area at any one time; considerable decrease in stress amongst reception staff; increasing trust from Travellers, with women beginning to attend for regular screening and steadily increasing use of Child Health Surveillance clinics and immunisation clinics; Travellers driving considerable distances to attend the surgery when travelling; Traveller forum attendance entirely female so far; and failure amongst older male Travellers to attend early when cancer is suspected. No further evaluations have been identified. **Grade [G1, NIE]**

Specially commissioned GP services for adult Gypsies/Travellers in unauthorised encampments

Central Bedfordshire and NHS Bedfordshire Clinical Commissioning Group have commissioned Horizon Health Choices (founded in 2006, Horizon Health Choices comprises 25 GP practices in North Bedfordshire with a combined patient list size of over 170,000) to manage the planning and delivery of care for adults within unauthorised encampments and written as standard operating procedure for planning and delivery of care to children and their families within unauthorised encampments to assist health visitors (health visitors to attend all unauthorised encampments with children to assess and care plan the needs of these families)⁸⁴. No evaluations are available of this service. **Grade [G4]**

3.2.5 Components of interventions cited as good practice

Hand-held patient records

Many studies of the health of Travellers have recommended the use of hand-held patient records (Save the Children, 1983; Lawrie, 1983; Cornwell, 1984; Crout, 1987; Streetly, 1987; Pahl & Vaile, 1988; Feder, 1989; Durward, 1990; Feder *et al.*, 1993; Neligan, 1993; Acton *et al.*, 1994; and Bunce, 1996)⁸⁵. However, there are few descriptions of pilot schemes that have implemented this intervention and a dearth of formal evaluations.

⁸⁴ NHS Bedfordshire. Annual Report 2010/11. Bedford: NHS Bedfordshire, 2011;

⁸⁵ For full references, see: Aspinall PJ. A review of the literature on the health beliefs, health status, and use of services in the Gypsy Traveller population, and of appropriate health care interventions. Cardiff: Health ASERT Programme Wales, 2005.

In *Scotland* pilot schemes on hand held records were undertaken in Dumfries and Galloway and Forth Valley. Strong support was expressed in the Official Inquiry (Scottish Parliament, Equal Opportunities Committee, Official Report, 5 June 2001, col. 1256) to roll out the system across Scotland to help Gypsy Travellers access services and maintain continuity of care. The Scottish Parliament's Equal Opportunities Committee recommended that resources should be made available to Health Boards to develop the use of patient hand held records. The Scottish Executive's response to the Equal Opportunities Committee Report of 2001 (Scottish Executive, 2001a) on this matter is that the use of patient hand held records will be considered as part of the planning necessary to meet the Scottish Health Plan commitment. Save the Children Scotland (2000) cite patient held records as one of a few examples of good practice. The Scottish Executive's Race Equality Advisory Forum (REAF, 2003), in their Health and Social Care Action Plan, also recommend that for Gypsy Travellers the Scottish Executive Health Department give early consideration to the feasibility of developing patient-held health records throughout Scotland. Patient hand-held records were thus developed, over 100 Gypsies or Travellers being involved in this process.

The 2001 EOC inquiry led to the roll out of the patient hand-held record, copies being distributed to health boards by the National Resource Centre for Ethnic Minority Health. GP practices were sent sample hand-held records and given the opportunity to order as required. Around 1,060 hand-held records were ordered, the largest requests coming from Greater Glasgow and Clyde, and Lothian. As part of the roll-out 16 awareness-raising events were held in 2007 following two pilot sessions in early 2006. Currently (2012) NHS Scotland has 1,290 copies of the hand-held record in stock, responsibility for ongoing awareness-raising resting with individual health boards.

Evidence for the effectiveness of hand-held records in Scotland is mixed. An evaluation of take-up and questionnaire survey for recipients of the hand-held record were carried out in 2009: however, only 9 of 170 questionnaires (5.3%) were returned⁸⁶. The use of the hand-held record was up to the individual Gypsy/Traveller: while some users found them very effective, others chose not to use them fearing that they would become an ID card. Some Gypsy/Traveller witnesses stated that moving from standard to hand-held records could cause problems, including falling between the two types. The Equal Opportunities Committee 3rd Report (2012) found take-up variable between GP practices. While roll-out had been relatively successful in Dumfries and Galloway, '…in practice, some GPs will accept the use of hand-held records, and others will have no knowledge of them so will not – this difference can even occur between two GPs at the same practice' One GP witness told the Equal Opportunities Committee that using the hand-held record effectively doubles the amount of

⁸⁶ Equal Opportunities Committee, 3rd Report, 2012, Minister for Public Health, Written submission, 30 May 2012.

paperwork to be undertaken as standard records still need to be filled out, probably explaining the limited take-up.

The 2012 Equal Opportunities Committee 3rd Report concluded that 'Introducing hand-held records does not seem to have tackled any underlying discrimination against Gypsy/Travellers accessing practitioner services, despite awareness-raising built in to the roll-out'. Health and social care professionals suggested identifying on popular travelling routes GP practices – so-called 'open-house' or drop-in practices - that would accept Gypsies/Travellers as patients without registration, would share medical records, and see community members at short notice, with the prospect that this would require additional funding. A full review of hand-held records for Gypsies/Travellers by NHS Scotland is currently under way in Scotland, the Equal Opportunities Committee highlighting as issues that hand-held records should be a voluntary option for Gypsies/Travellers themselves as opposed to health boards/GP practices, the paperwork burden of filling out hand-held *and* standard records, and the need for more extensive awareness-raising as part of the roll-out. **Grade G2 [IE]**

A number of authorities in *England* are addressing this issue. East Sussex, Brighton and Hove Health Authority recommend the development of hand held family records⁸⁷. A conference exclusively on Traveller health issues, held at Wisbech, Cambridgeshire in March 1995, identified as a main issue the reluctance of some GPs to register Travellers as patients and the need for hand held records, a recent report stating that a hand held medical records system would be piloted with GPs in the near future (Cambridgeshire County Council, Cambridgeshire Travellers Research Group, 2002). Herefordshire Primary Care Trust (PCT) is developing patient held records (as part of a more general service innovation) (Commission for Health Improvement (CHI, 2002)).

In its National Strategy for Traveller Health, *Ireland*'s Department of Health and Children (2002) recommended the introduction of patient and family held records for Irish Traveller families, including a pilot project to identify how a patient and family held record system would work for the Traveller Community. The Department suggests that such records might contain information on a patient's medical history, all general practice and hospital consultations, obstetric history, and details of prescribed medicines, the use of which by Travellers would be voluntary. A Working Group of Traveller organisations, members of the Traveller Health Advisory Committee, the Irish College of General Practitioners, and Public Health Nurses working with Travellers, are drafting the content and design of a durable and user friendly patient and family held record to be used by all Health Boards and the Department stated that the introduction of the new record on a nationwide basis should commence not later than June 2003.

⁸⁷ Subsequent take-up of hand-held records appears to have been variable in the area (personal communication, Zoe Matthews, March 2013).

Although there are reports of effective pilots of a system of patient held records for use by Traveller families in the UK, no evaluations of these pilot schemes have been identified. However, the strength of support for this practice across many statutory and other agencies suggests that it is an effective intervention. The National Association of Health Workers with Travellers (NAHWT) was reported to be seeking government backing to launch and promote the use of a national client held record for Travellers (Van Cleemput, 2000). The use of patient-held records by the refugee population has been recommended (Jones & Gill, 1998). Support for patient held records has also come from the Welsh Institute for Health and Social Care (Hart, 2002) and the principle of moving towards patient held records was accepted at a policy forum of the Wales Labour party, with the prospect of a working party to take this forward (Labour Party Wales Policy Forum, 2001). In evidence given to the Welsh Assembly Equality of Opportunity Committee's Review of Service Provision for Gypsies and Travellers (EOC, 2003), health professionals reported the successful use by Gypsy Traveller families of parent-held child health records and of the development in Wrexham of an adult health passport to record medical details.

The Pacesetters Programme provides the latest implementation of the patient adult health record. Five NHS Trusts in the West Midlands SHA and South East Coast SHA collaborated with members of the Gypsy/Traveller community to design a hand held health record and to pilot its use in supporting access to healthcare and facilitating continuity of care. The two regions commissioned a staff training programme with trainers and community members delivering twenty sessions, reaching 229 staff across the two regions. At the time of the evaluation GP practices were also receiving separate training. The training has been evaluated positively by Van Cleemput *et al.* (2010), with particular reference to the opportunity to learn directly from Gypsy/Traveller community members. At that time records distribution and completion of baseline health information was in progress and there were plans to monitor use. The Bristol Pacesetter site has shown an interest in using the patient adult health records in their area. **Grade [G1, IE]**

A research review of the practical problems surrounding patient-held records and ethical arguments for and against them (Gilhooly and McGhee, 1991) concluded that 'there are no substantial practical drawbacks and considerable ethical benefits to be derived from giving patients custody of their medical records'. Further, a pragmatic randomised controlled trial of a patient held record used by the patient and healthcare professionals, with around 500 patients living in the environs of Swansea, found that the record was significantly helpful to patients preparing for appointments, reducing difficulties in monitoring their own progress, and helping them to feel more in control (Williams, Cheung, *et al.*, 2001). The investigators recommended that it should be made available to patients on request and used by them according to need.

3.2.5 Scrutiny reviews of maternity services: South Somerset and Southwark Councils⁸⁸

While scrutiny reviews are not, in themselves, service interventions, they are included here as important prerequisites to the development of interventions (but are not allocated an evaluation grading). Both are National Inclusion Health Board sponsored reviews. <u>South Somerset</u> District Council focused their review on exploring access to antenatal, perinatal, and post-natal maternity services for the local Gypsy and Traveller communities in South Somerset. The reported successes of the review were: the highlighting of areas of good practice and sharing the lessons/learning to improve cultural appreciation and access; the building of relationships with Gypsy/Traveller communities, their specialist organisations, & NHS Trusts; definition and communication of the value of district council health scrutiny; and a triggering to update the Council's JSNA to address Gypsy/Traveller needs. The main learning points were recognition of the diversity in the local Gypsy/Traveller populations, including their different needs and experiences.

The return on investment calculation for this scrutiny project looked at 3 indicators: the value of increased access to maternity services and improved patient experience, the value of improved access to GP and primary care services, and the value of increased networking and awareness building of the needs of Gypsy/Traveller communities. The potential savings were estimated at £5,440 against review costs of £1,599. The qualitative benefits encompassed Gypsy/Traveller needs included in the JSNA, partnership working with NHS trusts, promoting health inequalities systems, raising awareness & sharing information, focusing on the patient experience of Gypsies/Travellers, and networking between specialist Gypsy/Traveller agencies and health services.

<u>Southwark</u> Council's scrutiny review focused on maternal health and early years services for Gypsy/Traveller mothers and young children. The work with Gypsies/Travellers was used to pilot wider health inequalities work with marginalised groups. The successes were identified as: an effective stakeholder event & interagency networking; a (gender) focus on the experiences of Gypsy/Traveller women; learning about wider Gypsy/Traveller experiences; the recommendation of an overarching Southwark engagement framework; highlighting the benefits of better coordination of domestic violence services for women; and ensuring Gypsy/Traveller issues are included in the Council's long-term housing strategy. Reported learning points included: building relationships with specialist Gypsy/Traveller organisations; an understanding that wider determinants of health impact on maternity outcomes; and the contribution of the stakeholder engagement to the review.

⁸⁸ Cook B, Cutler B, Murphy L., Turner S. *Valuing Inclusion. Demonstrating the value of scrutiny in tackling inequalities.* London: The Centre for Public Scrutiny, 2012 (April).
The calculation of return on investment for the scrutiny project looked at 4 financial indicators: value of increased access to maternity services; value of improved access to GP and primary care services & a reduction in the use of A & E; return on investment of early intervention approaches; and impact on employment. The potential savings were estimated at £20,930, against review costs of £1,820. Qualitative benefits encompassed better awareness of Gypsy/Traveller issues locally, better partnership working, contributions to a strategic review of housing, the development of an engagement framework, and identifying access to domestic violence services.

3.2.6 Access to and use of Secondary Care Services

Somewhat fewer findings have been reported with regard to hospital admission/treatment and the prevention of hospital readmissions. The lack of ethnic coding for Gypsies / Irish Travellers on the HES inpatient, outpatient, and A & E datasets has precluded analysis of patterns of utilisation of these services (so there is a lack of analytical findings compared with that for the homeless). They have been accorded relatively little attention in NHS Trust annual reports. Gypsies and Irish Travellers are a relatively small community nationally (57,680 in the 2011 Census for England and Wales, though likely to be substantially undercounted) and few research studies have focused on the use of secondary health care services by this group. One important study is that undertaken by Hall *et al.* (2010) of Gypsies/Travellers' use of urgent care services (including hospitals) in Brighton and Hove⁸⁹.

There is a strong argument to remedy the lack of adoption of the 2011 Census ethnic coding in England, especially in Hospital Episode Statistics. A study of hospital discharge records in four NHS boards in Scotland (where completeness of ethnic coding was good) found that the risk of acute myocardial infarction and coronary heart disease admission was statistically significantly higher in South Asians and Other White (including Poles and Gypsies/Travellers)⁹⁰.

Most findings on secondary care use by Gypsies/Irish Travellers concern appropriateness of services and service gaps. Researchers have identified a gap in palliative care provision for terminally ill Gypsies and Irish Travellers⁹¹ and a lack of understanding of Gypsy and Traveller culture in hospitals. A recent health briefing suggested that poor provision for visiting family members and those with

⁸⁹ Hall V, Sadouni M, and Fuller A. *Gypsies' and Travellers' experience of using urgent care services within NHS Brighton and Hove boundaries*. Brighton & Hove: Friends, Families and Travellers, University of Brighton, and NHS Brighton & Hove, 2010.

⁹⁰ Connolly M, Millard A, Fischbacher C, & Guthrie C. The validity of hospitals' ethnicity data recording and an ethnicity analysis in four Scottish Health Boards: Acute Myocardial Infarction and Coronary Heart Disease. Accessed at: http://www.fphscotconf.co.uk/uploads/fph2012-

abstracts/FPH2012_The_validity_of_hospitals_ethnicity_data_recording_and_an_ethnicity_analysis_in_four_S cottish_Health_Boards__Acute_Myocardial_Infarction_and_Coronary_Heart_Disease-htm.pdf ⁹¹ Jesper E, Griffiths F, Smith L. A qualitative study of the health experience of Gypsy Travellers in the UK

³¹ Jesper E, Griffiths F, Smith L. A qualitative study of the health experience of Gypsy Travellers in the UK with a focus on terminal illness. *Primary Care Research and Development* 2008; 9(2): 157-65.

limited literacy skills contribute towards Gypsies and Travellers choosing to self-discharge from hospital early⁹².

Community engagement and peer advocacy

Many different types of advocacy are reported in the health and social care literature: professional advocacy (where the advocate will be a salaried or paid professional providing time-limited advocacy), citizen advocacy (the development of a longer-term one-to-one relationship between a partner and a volunteer advocate), self advocacy (which aims to allow a person to make their own choices and exercise their own rights), and peer advocacy (where the advocate will have similar life experiences, challenges or difficulties to their advocacy partner). Peer advocacy and the involvement of peers as educators and trainers appears to be crucial to good practice in health care interventions for the Gypsy/Traveller community.

3.2.7 Summary: Elements of good/promising practice in service models

With respect to the Pacesetter Projects, the evaluation highlighted key findings with respect to community engagement.

- Community engagement was a key emphasis, especially the need to consult community members at the outset on priorities for action.
- The projects showed a fluctuating commitment to community involvement centrally.
- The projects had a different understanding and experiences of community involvement.
- There were different levels of community involvement locally, giving rise to the following learning:
 - The needs for and development of a project must be decided with community members who must take ownership of it or champion it for it to be successful
 - Involvement through communication should be maintained through all stages of the project
 - o Flexibility is needed to allow for effective community involvement
 - o Confidence and trust are core issues
 - Facilitation through a trusted person should be provided to overcome barriers to participation
 - o The remit of community members as advisors or decision makers should be clear
 - Time and costs of community involvement need to be built in to local budgets.

⁹² Matthews Z. *The health of Gypsies and Travellers in the UK. A Race Equality Foundation Briefing Paper.* London: Race Equality Foundation, 2008 (November).

Cross-cutting themes arising from the projects included:

- The importance of process in developing lasting collaborations, confidence, and increased skills among community members
- Numerous changes of staff in the Pacesetter and Department of Health teams lead to communication breakdown and loss of continuity, resulting in a negative impact on project delivery
- The timeframe of projects needs careful consideration, two years being insufficient to embed real change. Bureaucratic delays in release of funds and in setting up service level agreements delayed the start of several projects, so trusts were at different starting points with respect to community engagement
- For evaluation to be effective, this needs to be built in and independent evaluators appointed before the start of projects to allow appropriate data collection systems to be put in place and baseline data collection undertaken
- Adequate dedicated time and administrative support is required for project delivery staff
- At the outset of projects the remit and remuneration of community members must be agreed
- Pacesetter projects are much easier to deliver in Primary Care Trusts as key professionals are more easily identified.

Implications for further research/evaluation

Note that these recommendations exclude findings from Professor Susan Carr's NIHR-funded project ('Outreach programmes for health improvement of Traveller communities: A pluralistic synthesis of evidence'. PHR reference no. 10/3004/02. This research started 1 June 2011 and has not yet been published. See: <u>http://www.phr.nihr.ac.uk/funded_projects/10_3004_02.asp</u>)

- 1. While the 'Market Harborough model' is widely regarded as best practice in the delivery of primary care services to Gypsy/Traveller communities, attempts to secure the wider adoption of this model have not gone beyond the publicising and promotion of this service in primary care frameworks and good practice guidelines. Research is needed on how implementation of the Market Harborough model can be fostered through financial incentives (including special QOF arrangements) or other funding arrangements and what the return on investment is with respect to secondary care costs (A & E and inpatient care).
- 2. In spite of a number of efforts to implement hand-held records in England and Wales and the mainstreaming of the innovation in Scotland, the evidence base remains poor on whether this intervention works. Though Scotland is now undertaking a comprehensive evaluation of hand-held records in Scotland, similar evaluative research is required in England and

Wales, focusing on current comprehensiveness (geographically) of use of hand-held records, impact on GP workload, and the feasibility of a national roll-out, including assessment of costs and cost-effectiveness of awareness raising *et al*.

- 3. Many Gypsy/Traveller voluntary/charitable organisations are now emerging as policy hubs in an endeavour to influence national policy. They are frequently reservoirs of expertise on how to engage Gypsy/Traveller communities and the training and employment of members of these communities in peer advocacy and education. Research is needed on how to embed this good practice in the voluntary sector in multi-agency working as much of it is currently short-term and many effective interventions are time-limited because of shortterm funding.
- 4. An increasing number of Gypsy/Traveller organisations are developing multi-media, particularly video and online content (e.g. for maternity care and mental health/well-being) to address health issues relating Gypsies and Travellers. However, there has been little evaluation of different multi-media formats, particularly their efficacy in conveying health information to community members. There may be scope to undertake RCTs of different combinations of information presentation and communication with respect to the acquisition of health knowledge or as part of attempts to increase the uptake of particular preventive health care interventions.
- 5. Most of the good practice examples of interventions focus on specific components to improve health and access to healthcare. However, there is a paucity of holistic, multi-agency interventions that address the full living environment: site location, layout and facilities, sustainability of the living environment, access to schools, employment opportunities, and healthcare, etc., all of which impact on health. Research is needed to investigate ways in which government and service providers can develop a broader and more holistic multiagency approach to health and healthcare interventions (a start has been made on ITMB's work on the relationship between health and accommodation which is funded by the National Inclusion Health Board).
- 6. Full engagement with the Gypsy / Traveller community emerges as key to the successful outcome of health and healthcare interventions. **Different models of community engagement require evaluation to identify which are most effective and best enhance the community's ability to address its own health needs**. There are many different models in needs assessment: community-based participatory research, empowerment evaluation, participatory or community action research, and participatory rapid appraisal. These have their corollary in the design and implementation of interventions and evaluation work. Some

attributes that appear to contribute to success include willingness to share power (equitable power); interventions developed and agreed in partnership with community members; practices that enable communities to increase their capacity to address their health issues, through provision of resources and funding to train, employ, and build capacity of community members (capacity building); the use of formal agreements that set out responsibilities, ownership of projects, and dispute resolution; and a bi-directional flow of communications. The structures and frameworks needed to deliver these components of good practice require evaluation.

3.3 Homeless persons

Definition

In this report people who are homeless and vulnerable are defined to encompass three groups, in accord with Department of Health definitions of the vulnerable homeless: rough sleepers, individuals in the hostel system, and those sofa surfers and squatters who cycle into rough sleeping and the hostel system (this last group being difficult to measure). This definition excludes persons living in overcrowded or unfit homes and 'priority' individuals in temporary accommodation, some of whom may also be vulnerable. The three key groups are identified as it is generally agreed that these people have particularly high health needs and are hard to reach through mainstream services⁹³.

Policies on people who are homeless

Policy on people who are homeless has been formulated through the Ministerial Working Group on Preventing and Tackling Homelessness, set up in 2010 to coordinate cross-government work to tackle and prevent homelessness⁹⁴, statutory bodies such as the Greater London Authority, and by a range of voluntary sector organisations. It has focused on a number of issues: support for vulnerable single homeless men and women (who do not generally fall within the 'priority need' groups under the homelessness legislation); the position and needs of migrants who accounted for more than half of London's rough sleepers in the first quarter of 2010-11; capturing and flagging people at high risk of homeless people to health provision, including those below the threshold for referral to specialist services, and to training to help homeless people progress towards work; the investigation of measures to prevent people coming on to the streets, including stopping the discharge of people from hospitals and prisons with nowhere to go; and ensuring that housing benefit changes do not impact on safety net homelessness services for the most vulnerable.

The Ministerial Working Group's dual focus has been: i) the prevention of homelessness, particularly earlier intervention, that focuses on large numbers of people at risk of homelessness who do not access support from housing authorities or do so only at a late stage; and ii) the improvement of the lives of those people who do become homeless. Two reports have been published: *No Second Night Out* (July 2011) and *Making Every Contact Count* (August 2012). The national roll-out of No Second

⁹³ For a useful discussion, see: Office of the Chief Analyst. *Healthcare for Single Homeless People*. London: Department of Health, 2010 (March).

⁹⁴ See: Minutes of the Ministerial Working Group on Preventing and Tackling Homelessness, 20 November 2012, 28 February 2012, 7 September 2011, 14 March 2011, 12 October 2010, & 16 June 2010.

Night Out builds on the Greater London Authority's pilot programme to identify new rough sleepers and ensure they can access the support they need so that they do not have to sleep rough on the streets. The six month pilot began in April 2011 and by February 2012 the phone line had taken 4000 calls from the public and 700 people had been helped off the streets, a success rate significantly higher than conventional outreach services with only 14% of the 700 rough sleepers helped returning to the streets. Challenges include the need to extend the service beyond the 10 inner London Boroughs in the pilot to achieve a cross London strategic response with coordination of hostel bed spaces and outreach services, ensuring that local authorities provide good quality advice to single homeless people and a rapid response from their housing options teams, and the 52% of London's rough sleepers who are foreign nationals (as revealed in CHAIN data). The national roll-out has been driven by DCLG's prioritisation of single homelessness (including additional funding to support local authority services and a national rough sleeper reporting line). The DCLG is also supporting the GLA's work with embassies to ensure foreign nationals are aware of the realities of moving to England before they leave their home countries.

In addition rough sleeping and statutory homelessness statistics have been improved. DCLG introduced a new methodology for the rough sleeping statistics in 2010 to give a more accurate national picture. The statistics now give a snap shot of the number of rough sleepers on a single night and DCLG is further considering how best to capture data on the number of nights spent sleeping rough.

Work on prevention has been informed by Professor Suzanne Fitzpatrick and colleagues' 'Multiple Exclusion Homelessness in the UK: key patterns and intersections' research which focused on rough sleepers and people accessing support services in seven UK cities. This has yielded important findings on the risk factors for homelessness and the Ministerial Working Group has linked these (especially those factors stemming from childhood) with the government's 'Troubled Families' work and the value of the case worker approach where a single named individual is responsible for bringing services together. Its strategy is using learning from the Multiple Exclusion research to pinpoint key early intervention points and identify the department or agency responsible for delivering them. The strategy is considering how services work together around the individual.

Government policy recognises the key role played by the voluntary sector. A £20 million Homelessness Transition Fund supports critical front line voluntary sector services and the government supported voluntary sector partners to develop StreetLink, a mobile website and national telephone line to enable members of the public concerned about rough sleepers in their area to provide details of location so that these individuals can be connected to local services and helped off the streets. The site is now live allowing members of the public or rough sleepers themselves to report incidences. Other collaborations include that between DCLG and Crisis on improved support for single people to access private rented housing.

Other government policy initiatives that affect the homeless population include: the Department of Health's work to improve the hospital discharge process for homeless groups and the duty to tackle health inequalities; the launch in April 2013 of the new Health and Well-Being Boards which offer an opportunity to improve co-ordination between NHS and housing services and will support enhanced Joint Strategic Needs Assessments; DWP's work to allow early access to the Work Programme for homeless people and the maintaining the housing element of the Universal Credit for prisoners serving sentences of six months or less; the Localism Act clauses that allow local authorities to end the main homelessness duty with an offer of suitable accommodation in the private rented sector and which are accompanied by a 'suitability order' which ensures that this accommodation is good quality and suitable; the Ministry of Justice's announcement on additional rehabilitation support on offer to prevent re-offending, including the provision of mentors to meet newly released offenders at the prison gates and the expectation that they will help them with housing and employment needs; and new legislation that makes squatting in residential buildings a criminal offence.

Peer Advocacy is contributing to policy development via the Homeless People's Commission, a group of former homeless people who had come together to help tackle homelessness and improve services. They have made recommendations on how to improve policies and services for rough sleepers and are involved in a number of projects as commissioners: the Peer Health Advocate Project uses peer volunteers to accompany homeless people to health appointments, thereby helping to reduce A&E admissions and missed appointments and securing sustained treatment; the Project Assessment Team at Two Saints Housing Association use clients to assess the quality of services and make recommendations for their improvement, and Cyrenians in Newcastle use former homeless people on their outreach team which has helped over 100 people off the streets. The London Pathway Project also trains and supports new cohorts of homeless healthcare practitioners and care navigators to help implement their models of service.

Finally, a number of innovative and effective policies are being pioneered by the London Pathway Project. Pathway has developed a model of integrated healthcare for single homeless people and rough sleepers that puts the patient at the centre of their own care. While its initial focus was to improve healthcare for homeless people admitted to hospital, this has led to the development of models that follow up patients long after they have been discharged and consideration of intermediate care centres for chronically sick homeless patients. Pathway's core services encompass needs assessment and start-up, supporting acute hospital ward rounds, homeless health nurse practitioners, care navigators, post discharge support, accreditation, professional support and training, and research

and service development support. The charity has developed a range of operational resources for hospitals wishing to adopt the Pathway model.

Access to primary care

Homelessness is known to be associated with a greater burden of health problems, including premature mortality, to complicate treatment by virtue of the frequent presence of multiple morbidities, and to disrupt the continuity of care through, for example, self-discharge and extended hospital stays. There is substantial evidence for the following:

- Significantly higher rates of physical and mental illness, including 'tri-morbidity' (the combination of physical ill health, mental ill health and drug or alcohol misuse, the latter the most common reasons for hospital admission) than the general population; amongst St Mungo's homeless residents, half had mental health illnesses, 32% an alcohol dependency, 63% a drugs problem, 43% a physical illness, & around a third a condition that was not being treated
- Common health problems amongst homeless people include mental ill-health, physical trauma, skin problems, respiratory illness, blood-borne viruses, and drug/alcohol dependence,
- Homeless people experience many barriers to accessing mainstream primary care and specialist provision is limited and variable (with respect to permanent registration, for example)
- Homelessness is associated with significantly increased mortality rates (homeless people being 3 or 4 times more likely to die prematurely than their counterparts in housing); of deaths that occur in hostels or while registered with homelessness services, the average age at death is 40-44 years; these deaths are associated with acute and chronic medical conditions exacerbated by rough sleeping
- Premature mortality is associated with drug misuse: a study in Glasgow found that a homeless
 patient admitted to hospital with a drug problem was 7 times as likely to die over the next 5
 years as a patient with the same drug problem but not homeless
- Homeless people faced many barriers in accessing primary care, including lack of proof of address for registration, poor engagement skills/chaotic lifestyles, and late seeking of assistance
- The most common reasons for hospital admission of the 'no fixed abode' population include: toxicity, alcohol problems, and mental health problems
- Homeless persons in England attend emergency departments five times more frequently as those who are not homeless, are admitted 3.2 times as often, and have inpatient stays three times as long as the general population aged 16-64 (though mostly explained by differences in

case-mix). These characteristics result in inpatient costs eight times higher for homeless patients compared with the general population aged 16-64.

- The long-term effectiveness of hospital care is diminished by lack of a stable home environment
- Integrated and holistic care across primary care, mental health and drug/alcohol services, social care, and housing - is frequently problematic (because of local authority residence rules, for example)
- Rough sleeping after hospital discharge creates many challenges to the health of the homeless, including healthy eating, funding needed travel, and finding the space for rest and recuperation; difficulties in adhering to medication, other instructions, and follow-up appointments may increase hospital admissions and readmissions

Access to primary care is widely reported to be poor:

- In a Homeless Link national audit of the health/wellbeing of people who are homeless (n==c700)⁹⁵, 85% of clients said they were registered with a GP, the majority permanently. Nearly 1 in 10 (9%) said they had been refused access to a GP or dentist. 82% had been to a GP at least once during the last 6 months.
- An earlier (2002) Crisis study⁹⁶ indicated that the homeless client group were 40 times more likely not to be registered with a GP than the general population.
- Homeless Link's 2009/10 audit of health needs in Bristol found 89% of homeless persons were registered with a GP, most permanently. Only 40% of clients were registered with a dentist.
- The Office of the Chief Analyst 2010 report⁹⁷ on single homeless persons identified as the chief barriers: mainstream GP practices may require proof of address for registration; homeless people generally have poor engagement skills and chaotic lifestyles, making it difficult for them to book and keep appointments; and some will defer seeking assistance until their health is critical as they often have more immediate needs.

⁹⁵ Homeless Link. *The health and well-being of people who are homeless: Evidence from a national audit.* London: Homeless Link.

⁹⁶ Crisis. Critical Condition. 2002.

⁹⁷ Office of the Chief Analyst, Department of Health. *Healthcare for Single Homeless People*. London: Department of Health, 2010.

Specialist primary care service models

There have been a number of attempts to categorise primary care services for homeless persons. Using a database of 125 primary care services provided to homeless people across England, Chiddick (2007)⁹⁸ categorised PCT services into five groups:

- <u>No specialist provision</u> (n=48)
- <u>One outreach team</u> provided by individual nurses, health visitors and doctors or by teams, without dedicated facilities (n=31)
- <u>One GP practice offering temporary registration</u> (n=12)
- <u>One GP practice offering permanent registration</u> (n=43)
- <u>More than one specialist homeless service</u> (n=16)

Thus, 38% of PCTs provide no specialist provision, while a quarter (25%) provide just one outreach team and a further 10% providing temporary registration for homeless people in one GP surgery.

A somewhat similar analysis by the Office of the Chief Analyst, Department of Health, has suggested that a third of PCTs did not provide any specialist homelessness service⁹⁹. Amongst the other two-thirds of PCTs that did provide specialist homeless primary care services, four models of care have been identified, that can be located along a continuum of least specialised to most specialised and which is likely to be related to the size of the homeless population in the PCT area:

- (1) <u>Mainstream practices provide services for homeless</u>: A GP from a mainstream practice holds regular sessions for homeless people in a drop-in centre or sees them in his/her own surgery but may not register patients and does not provide 24/7 provision
- (2) <u>An outreach team of specialist homelessness nurses</u> provide advocacy and support, dress wounds, etc. and refer to other health services including dedicated GP clinics but is unlikely to register patients and no 24/7 provision
- (3) <u>Full primary care specialist homelessness team</u>: A team of specialist GPs, nurses and other services (CPN, podiatry, substance misuse specialists) provide dedicated and specialist care, co-located with a hostel / drop-in centre: this service usually registers patients and provides 24/7 cover. This model offers significant potential in terms of healthcare as it tailors the service to meet the needs of the homeless and circumvents some of the access issues for those with mental health problems or drug/alcohol dependency. The configuration of this service is likely to depend on the size of the homeless population: 'Such a model is likely to

⁹⁸ Chiddick L. *Health service provision for the homeless across England – A mapping, classification and analysis.* MPH Dissertation, University of Leeds, 2007 (August).

⁹⁹ Office of the Chief Analyst. *Healthcare for Single Homeless People*. London: Department of Health, 2010 (March).

be justifiable in the major urban centres with larger homelessness populations. The level of service that can feasibly be provided by a full primary care specialist homelessness team will be greater the larger the local homelessness population. Services that are suitable in areas with a very large population can include frequent walk in sessions or regular clinic sessions with Consultant Psychiatrists'.

(4) <u>Fully coordinated primary and secondary care</u>: A team of specialists spanning primary and secondary care provide an integrated service including specialist primary care out-reach services, intermediate care beds and in-reach services to acute beds. According to the Office of the Chief Analyst: 'No English PCTs are currently known to provide a fully integrated care model including a step-up/step-down secondary care unit, though pilots are underway that seek to increase the integration of care for homeless patients', adding: 'It can be argued that the major urban centres such as London, Manchester, Birmingham and others have a sufficiently large homeless population for fully integrated primary and secondary care'.

Examples of the models:

Care models 1 and 2: Mainstream services that provide some services for the homeless with/without outreach services

<u>Barking and Dagenham NHS PCT:</u> This PCT first established a national locally enhanced service (LES) for the homeless in April 2009-March 2010, signed up for by 24 GPs¹⁰⁰. A price of £40.72 was set per eligible patient per annum. For the purposes of the LES, homeless people were defined as rough sleepers, hostel and night shelter residents, bed and breakfast residents, squatters, and people of no fixed abode staying temporarily with friends or relatives. The service was designed to ensure that homeless people have equal access to appropriate levels of service from GP practices to ensure that their health needs are effectively tackled; GPs are provided with the knowledge, training, and resources to enable them to deal effectively with homeless peoples' health needs; and GP services are empowered to treat the health needs of homeless people into local communities. The specific service criteria in the specification encompass:

- Up to date register of homeless people
- Liaison with statutory services and homeless agencies
- Awareness of, and attendance at, homeless forum meetings

¹⁰⁰ Barking and Dagenham NHS Primary Care Trust. Locally Enhanced Service for Homelessness (LES26). Accessed at: http://www.barkingandhaveringlmc.org.uk/updates/documents/LES26_Homelessness0910.pdf

- Flexible registration procedures to allow patients to register as permanent if they so wish (those of established homeless status)
- Explicit policy to see such patients at short notice and to provide flexible times in surgery
- Onward referral to intermediate mental health services or CPN services as appropriate.

Monitoring and evaluation were built into the agreement: 'Participating practices will be expected to submit quarterly data on the number of patients newly placed on the homeless patient register by the practice in the preceding quarter. The PCT would also expect practices to carry out some form of audit on this information (e.g. an audit of physical and mental health problems experienced by the patients), or to review the operation of the service (e.g. patient feedback). This work could provide the evidence that enables the practices and PCT to re-design and re-specify the service in the medium term'. **Grade [G4]**

Care model 3: Dedicated GP practices that provide full primary care specialist homelessness team

As with asylum seekers/refugees, a service model of designated GP practices has been adopted by a number of PCTs (or unified health authorities in Scotland). These include practices catering exclusively for the homeless population, some of which operate open access surgeries, and others where registration is limited to a diverse population of vulnerable groups, such as the homeless and asylum seekers.

- <u>The Edinburgh Homeless Practice</u> is an open access GP surgery for homeless people who are not registered with a GP. Grade [G4]
- Health E1 Medical Centre, Tower Hamlets, run by the East London NHS Foundation Trust, is a nurse-led PCT Medical Services Practice with GPs and specialist nurses. It was set up in 2000 to address the primary, mental healthcare and substance misuse needs of street homeless and hostel dwellers in the London Borough of Tower Hamlets. This is an area with a large number of hostels and day centres and which had experienced inappropriate use of local A&E and Walk-In Services by the homeless as a substitute for seeing a GP. The Health E1 practice defines the homeless to encompass street homeless, those living in local hostel accommodation, bed and breakfast or temporary housing along with squatters, refugees and asylum seekers. It offers full, permanent registration with the practice thereby providing continuity of care. The service offers routine appointments within 48 hours, appointment bookings 2 weeks in advance, booking of a GP telephone consultation, and a daily walk-in clinic. Health E1 offers a wide range of other services, including home visits, psychologist, health visitors, family planning, blood clinics and blood borne virus team, new patient health checks, substance misuse clinics, mental health checks, and alcohol services. The practice has highlighted the significant demand for certain medications, like paracetamol, ibuprofen, and

knee supports (usually bought over-the-counter), to be supplied and regularly replaced when stolen. Grade [G4]

- The Greenhouse Walk-In Centre, Hackney, also run by East London NHS Foundation Trust, provides health care services and housing and welfare advice for people who are sleeping rough or are vulnerably housed: this population may encompass people with a drug or alcohol problem, be a street sex worker, be a refugee or asylum seeker, have mental health issues, or be released from prison, care or the armed forces. It is a specialist nurse-led service, with input from GPs. It offers a full range of medical services, including full registration with health assessment, foot health, psychiatry, and psychological services. Grade [G4]
- <u>The Dawn Centre, Leicester</u> provides temporary accommodation for single homeless people and childless couples and includes a 42 bed night shelter, a YMCA drop-in-centre, and a primary health care centre. All patients are homeless at registration but not necessarily rough sleeping. Anyone classed as homeless in Leicester can register at the health care centre and attend a drop-in or pre-booked appointment. The dedicated team includes general practitioners, nurses, community psychiatric nurses and a drug worker, who provide multidisciplinary care for their patients. **Grade [G4]**
- The York Street Health Practice, Leeds was formed in January 2011by a merger of the Health Access (HAT) and No Fixed Abode (NFA) services to offer healthcare for the vulnerable transient and homeless population in Leeds. This innovative new service provides primary care to the homeless and 'vulnerably housed' in Leeds whose health problems may include mental health, alcohol and drug use. The merged service provides an increased list size and registration for people currently seeking asylum. The new service provides primary care registration, GP and nursing service, mental health service, alcohol service, support service, and drug service (funded by Safer Leeds). Primary care registration is open to all adults who are homeless or vulnerably transient (including asylum seekers). It also provides new arrival assessment and screening for asylum seekers, an outreach service, and consultancy, advice and training. The dedicated multi-disciplinary team comprises mental health nurses, support workers, drug therapists, GPs, practice nurses, nurse practitioner, client support workers and administrative staff. Patients can refer by telephone, fax or email. Grade [G4]
- Three Boroughs Homeless Team: The Three Boroughs Homeless Team is a NHS funded primary care nurse-led team that runs open-access 'walk-in' health clinics in homeless hostels and day centres in Lambeth, Southwark, and Lewisham and started (in its current form) in 1992. Nurse Practitioners on the team independently treat minor illness and minor injuries without referral onwards to GPs or Accident & Emergency Departments where this is not needed. They also provide a variety of other primary care nursing services in partnership with local GPs. Nurses also undertake comprehensive health assessments on clients, thereby identifying clients in need of more complex case management for their chronic health needs.

The Homeless Team provides the primary care services at Cedars Road Hostel, in partnership with the Courtyard Surgery at Clapham. **Grade** [G4]. Since 2009 the Homeless Team have run an intermediate care pilot project at the 120-bed hostel, for those most at risk of death or disability at any one time (from early 2012 the scheme relocated to Thames Reach's Graham House in Vauxhall, see below: 'Intermediate care').

Other examples involving services for multiple vulnerable groups: Other examples include practices that have established specialist services for a range of vulnerable groups. The Sanctuary Practice in Hackney was set up for homeless people and asylum seekers (the service for homeless people operates from a separate site). In Newham, where local GPs were refusing to register vulnerable people such as the homeless, drug users, and asylum seekers, two Transitional Practices were set up which register the homeless, drug users, and asylum seekers and in addition anyone else having difficulties registering with a standard GP. The practices' patients comprise asylum seekers (10%), other migrants (75%), homeless 10%, and others, such as undocumented migrants (5%). The New Arrivals Practice, Southampton, registers asylum seekers (3%), other migrants (85%), and homeless (12%). The Quay's Practice, Hull, registers asylum seekers, refugees, other migrants, homeless, drug and alcohol users, and exoffenders. Around 30% are asylum seekers. The Dove Practice, Doncaster, was set up in 2003 for vulnerable groups and registers asylum seekers, refugees, other migrants, homeless people, substance misusers, adults with learning disabilities, young people in housing, and recently released prisoners. Migrants comprise around 70% of the patient population. Bevan House, Bradford, is a PMS Practice set up in 2003 to register asylum seekers, homeless people, and other vulnerable groups, as well as local residents. All Grade [G4]

Care model 4: Fully coordinated primary and secondary care

There are relatively few examples of this model, the most frequently cited being the services provided in Boston, USA, for homeless people, but with similar innovative services now being developed in London.

Integrated health services for homeless people in Boston, USA¹⁰¹

The example of joined up primary care and acute care demonstrated by the Boston service was cited by the Office of the Chief Analyst, Department of Health, as a working example of the way care for homeless people could be integrated, noting that it is not representative of health care provided to homeless people across the USA.

The team of doctors, nurses, social workers, and assistants follow their patients through primary care, in specialist clinics, in A and E, inpatient, medical respite, and home visits when homeless people find housing. The service comprises:

- A medical walk-in unit for homeless people for primary care
- Out-reach clinics to 70 community-based locations
- A 90-bed step-up/step-down unit based in Boston City Hospital providing acute and sub-acute beds, pre- and post-operative, recuperative and rehabilitative care to homeless people who require preparation prior to treatment or who are too unwell to withstand life in shelters or on the street, following hospital treatment
- There is a special service catering for rough sleepers, involving intensive follow-up to achieve continuity of care from the streets to Intensive Care Units and respite.
- Preventative care is also offered to the most hard to reach homeless persons (e.g. flu vaccines and prenatal care)

The notable achievements of the Boston model include medical respite care that bridges the widening gap between hospitals and shelters, an electronic medical record system that coordinates care and monitors quality measures across 2 hospitals and 80-plus shelter and street clinics, multidisciplinary teams that integrate medical and behavioural care and ensure continuity of care, the inclusion of the homeless in the programme's governance and design of services, and consistent provision of preventive services.

Grade [GI, IE]: in cited & other publications.

Pathway Healthcare for Homeless People¹⁰²

The setting for the intervention is University College London Hospital, a 900-bed, acute hospital trust in NW London. The intervention comprises a Homeless Health (nurse) Practitioner seconded full time to the hospital discharge liaison team. She accepts referrals and visits all homeless patients

¹⁰¹ O'Connell et al. The Boston Healthcare for the Homeless Program: A Public Health Framework. *American Journal of Public Health* 2010 (August); 100(8): 1400-1408.

¹⁰² A description of the intervention and its evaluation have been reported in a number of publications: Box A, Hewett A, Cumberbatch F, & Boyce T. *Pathway Healthcare for Homeless People*. London: The Health Foundation, 2012;

within a day of admission. A community GP attends the hospital for four half-day sessions to lead ward rounds and the process is supported by a Care Navigator, a person with an experience of homelessness who joins the ward round and supports the GP, nurse and patients with mentoring and support. A weekly multi-agency care planning meeting involves hospital teams, mental health teams and community housing, social care, drug and alcohol, and voluntary sector workers in coordinating and planning for discharge support of homeless patients.

This intervention has been evaluated by the hospital trust¹⁰³. Opinions on the qualitative impact of the service were sought from patients (n=20) and members of the homelessness team (n=10). A sample of published responses were all positive. Quantitative outcome measurement comprised the number & duration of admissions for homeless people. When 57 patients identified during needs assessment were compared with 57 consecutive patients treated by the intervention team, the average length of hospital stay decreased: the number of patients staying 6-10 days doubled (interpreted as a greater level of completed treatment), while the proportion staying over 30 days fell from 14% to 4% (interpreted as a reduction of the few very prolonged admissions). A summary measure of the number of bed days associated with homeless patients monitored from June 2009 (pre-intervention) shows a downward trend in bed occupancy in 2010 and 2011 (the first two full implementation years). Over the period 2008-11 the number of patients admitted and the total admissions each year had remained virtually unchanged, with no underlying downward trend in the average length of stay for all unscheduled admissions, while there was a reduction of 1000 annual bed days (30% reduction) for homeless patients, a net saving of around £100,000 a year. **Grade [G1, NIE]**

There are now a number of pilots underway (including Barts and the London NHS Trust and Brighton and Sussex University Hospitals NHS Trust) based on the Pathway model, incorporating homelessness hospital ward rounds and care navigators, people with experience of homelessness, who can offer emotional support and assertive outreach and link them up with services.

Other models or elements in the provision of care

1. Mobile health and dental clinics

Relatively little use has been made of this intervention in the UK though it is used in the USA and there are examples from Ireland. As with mobile clinics for asylum seekers and refugees, there are trade-offs between enhanced accessibility on the one hand and such clinics being a substitute for adapting existing mainstream primary care services.

¹⁰³ Hewett N, Halligan A, Boyce T. A general practitioner and nurse led approach to improving hospital care for homeless people. *British Medical Journal* 2012, Sep 28;345:e5999. doi: 10.1136/bmj.e5999.

<u>The Safetynet network for homeless health services</u> in conjunction with the Dublin Simon Community, the Chrysalis Community Drug Project and the Order of Malta, Ireland, has developed a mobile health clinic for homeless people and female sex workers. The service aims to bring primary healthcare and harm reduction services to these groups. The service began in April 2010, was formally launched in May 2011, and operates in a number of locations on the north and south side of Dublin City. The clinic was the idea of a GP with his own practice in the city who is chairman of Safetynet, a networking organisation including the Health Service Executive (HSE), GPs and the voluntary sector (but not a service providing organisation) for nurses, doctors and voluntary agencies providing primary health care to homeless people living in Dublin City and Cork City.

The aim of Safetynet is to offer a comprehensive primary healthcare service targeted at people who are homeless in Dublin. The project offers essential medical support to people who are homeless and who may not be in contact with mainstream services but also works to improve links and access to mainstream health and social services for people experiencing homelessness. Services available within the Safetynet network are general nursing assessments, vaccinations, counselling, chiropodist, GPs, blood testing, sexual health (male and female), safer injecting/harm reduction information, and referral letters to hospitals and other services. The bus belonged to the Eastern Regional Ambulance Service and was given to Safetynet. The mobile clinic now has a waiting area that will seat about five people, a toilet, a surgery and an area for tea, coffee and outreach work. On one weekday night it is operated by Chrysalis, which is a project that provides support to male and female drug users and their families, and provides a range of services to female sex workers. On another night it is run by the Dublin Simon Community's rough sleeper team which helps people with homeless and alcohol problems. Doctors are provided by the founder GP's training scheme and are supervised by senior medical practitioners. The Order of Malta, Ireland, provides emergency medical technicians. Operation hours are between 7pm and 11pm and the Mobile Health Clinic can be accessed by telephone.

A recent service utilisation review has been undertaken of the mobile health clinic¹⁰⁴. With respect to primary care services, between 19 April 2010 and 23 December 2010 66 clinics were operated. A total of 288 patients received medical care in the mobile health clinic during this period. 67% of the patients were male and 74% were aged between 19 and 30. During this period the main reason patients presented to the servicer was to receive treatment for addiction related problems related to injecting drug use, problem alcohol use, and polydrug use (27% of cases). 18% had respiratory-related

¹⁰⁴ Safetynet Network for Homeless Health Services, Chrysalis Community Drug Project, Dublin Simon Community, and Order of Malta, Ireland. Mobile Health Clinic. 2010 Service Activity Report. Accessed at: http://www.primarycaresafetynet.ie/uploaded_documents/2010_Mobile_Health_Clinic_Service_Activity_Repor t.pdf

illnesses, 8% for skin conditions, 8% for sexual health/pregnancy, and 7% for psychological complaints. In a fifth of cases patients were referred to other health services.

With respect to the harm reduction service, between 22 April and 23 December 2010 34 clinics were operated. During this period a total of 649 interventions were completed by the Rough Sleeper Team. There were 207 referrals to accommodation or the Homeless Persons Unit and 442 harm reduction interventions provided. Over 68% of the work carried out was the provision of safer drug use and health promotion advice and information, and needle and syringe-exchange services. Over a third of people using the Rough Sleeper Team's service were looking for accommodation. The Mobile Health Clinic is operated one night per week by the Chrysalis Community Drug Project. During the reporting period 32 clinics were operated by this community drug project outreach team. A total of 68 harm reduction interventions were provided, 38 related to safer sex information and advice and 30 related to personal safety. **Grade [G3, NIE]**

There are a few projects that provide the homeless and other vulnerable groups with dental care through a mobile clinic. <u>Southampton Primary Care Trust</u> provides the homeless, substance abusers and high social needs patients with dental care through a mobile dental surgery employed in areas of high deprivation where there has been no previous provision (a project listed by the NHS Institute for Innovation & Improvement¹⁰⁵). The clinic is mounted on a small van providing a full range of dental care to a predominantly 'drop-in' client group who would not be able to access the care in any other way. Similarly, <u>NE Lincolnshire NHS Primary Care Trust</u> is working with the homeless using a mobile dental clinic¹⁰⁶. A specialist homelessness health service provided by <u>South East Highland</u> <u>Community Health Partnership</u> in Inverness where a health team is linked to the Homeless Day Centre, includes a mobile dental clinic that visits the Day Centre fortnightly¹⁰⁷. All **Grade [G4]**

2. Hospital admission and discharge protocols and interventions

A number of hospital admission and discharge protocols for homeless people have now been published and have a number of elements in common. However, only a small number have been evaluated.

¹⁰⁵ See: NHS Institute for Innovation & Improvement

¹⁰⁶ NE Lincolnshire

¹⁰⁷ Highland NHS Board. Health And Homelessness Action Plan. Progress Report. 6 May 2008.

Wirral Hospital Discharge project

The project - set up in response to concerns that homeless patients were being discharged with little support with consequent poor health outcomes, continuing homelessness, and increased NHS costs - involved employment of a hospital link worker to train staff in appropriate discharge procedures and to provide some direct support for homeless patients. As the project progressed, elderly patients who could not easily return to their homes were included. Joint funding was secured from NHS Wirral and the Supporting People team at Wirral Borough Council for a one-year pilot starting in May 2010 and a further year was subsequently agreed. The project aimed to improve hospital discharge for homeless people/those at risk of homelessness by:

- Addressing homelessness in discharge policy and procedure;
- Developing a discharge protocol between the hospital and the local authority;
- Raising awareness of homelessness amongst hospital staff;
- Developing links between the hospital and community support/treatment services;
- Supporting patients through the discharge process to appropriate accommodation;
- Contributing to the understanding of local need and access issues.

A project evaluation by the Centre for Health Service Economics and Organisation, University of $Oxford^{108}$ indicated that it was largely successful in achieving key objectives. Between 2009-10 and 2010-11, the number of individual patients was virtually unchanged . However, there were falls in the number of episodes of 26%, in admissions of 18%, and in bed days of 26% (translating into similar falls *per patient*). Male patients, emergency care, substance misuse, and mental health issues all feature prominently amongst the no fixed abode episodes (reflecting patterns for the whole of England). There is a fall of a third in the number of episodes resulting in emergency readmission within less than 28 days between 2009-10 and 2010-11. These benefits translated into a reduction of around £26,500 (that is, around one-third at 2009/10 prices) in the total cost of no fixed abode episodes, a sum sufficient to offset a major part of the annual cost of the hospital discharge project. Although patient outcomes were not measured, there was likely to be an improvement in the health and quality of life for homeless patients. **Grade [G1, IE]**

¹⁰⁸ White J. *Homelessness and hospital discharge in Wirral: an investigation into the Hospital Discharge Project. NHS Brief No. 2.* Oxford: Centre for Health Service Economics and Organisation, 2011 (October).

London, Ontario: discharges from psychiatric wards to shelters or no fixed abode¹⁰⁹

To address a situation of 194 discharges a year of patients from psychiatric wards to shelters or no fixed abode in London, Ontario, a pilot project was developed that provided immediate access to an on-ward housing advocate and income support staff (facilitated through computer linkages to housing and income databases), thereby changing the usual policies relating to housing and start-up fees for a group of income support recipients. It was successful: 7 participants who received this additional assistance were still housed after 6 months, whereas 6 of 7 who received usual care were still homeless. Wider implementation involved the extension of the project to all acute psychiatric patients in a general hospital and to all patients within a specialized tertiary care psychiatric hospital. The intervention was shown to be successful across both acute and tertiary sites. The rate of discharge to homelessness decreased; those accessing the service were poor; and the cost savings from the programme exceeded the cost of implementation. Listed advantages of the approach included accessibility and convenience of services on site, positive influence on overall treatment plan, and feelings of independence and support. **Grade [G1, IE]**

3. Intermediate care

Intermediate care beds for homeless people are designated for patients who need less care than an acute bed but still need some nursing and rehabilitation (e.g., wounds dressed, a nutritional diet, overseeing medication, bed rest, recovery from injury, etc.). Neither rough sleeping nor hostels may provide a recuperative environment. The rationale for intermediate care beds for homeless people is set out by the Office of the Chief Analyst¹¹⁰:

- Intermediate care beds could prevent homeless people rotating between hospital discharge and readmission - often exacerbated by discharge against medical advice or disciplinary discharge, and thereby limiting continuity of care – by providing a place for homeless people to receive the care they need on hospital discharge
- Homeless people are not eligible to access existing intermediate care beds as they are predominantly for the elderly and often require an address on discharge & might also be unsuitable because of homeless persons' sometimes challenging behaviour

¹⁰⁹ C. Forchuk, R. Vann, E. Wilura, J. Hoch, M. Jeng, S. Kingston-MacClure, E. Jensen. P03-547 - Reducing psychiatric discharges to homelessness. *European Psychiatry* 2011; Volume 26, Supplement 1: 1717.

¹¹⁰ Office of the Chief Analyst. *Healthcare for Single Homeless People*. London: Department of Health, 2010 (March).

• TB is a specific condition that could be much better managed with an intermediate care facility because of the compliance that is needed with long drug treatment & the development of more drug-resistant TB

Three different forms of intermediate care have been identified: (i) an 'extra care' model; permanent hostel co-location; and a stand-alone facility.

3.1 <u>The extra-care model</u>: This would involve the spot purchase of extra care in existing hostels, care being commissioned as and when needed. This arrangement would allow care to be provided at a wider number of existing hostels as opposed to the hostel co-location and stand-alone facility options. Such a model could be facilitated by separating the provider of accommodation/support from the provider of care and the removal of the Supporting People ring fence. JSNAs could inform appropriate provision.

Liverpool City Council Intermediate Care

This approach has been used by Liverpool City Council to sustain hostel placement for a small number of entrenched rough sleepers. The additional services put in hostels include personal and cleaning services and extra bedding which has enabled individuals to remain in hostels rather than cycling between hostels, rough sleeping, and hospital admission; accompaniment to secondary care via the rough sleepers outreach team; and help with medical issues such as managing medicines and dressing wounds via dedicated homelessness outreach nurses. **Grade [G4]**

3.2 Co-location within a permanent hostel: Intermediate care beds could also be <u>co-located in a</u> <u>hostel</u>, with nursing care provided on an 18- or 24-hour basis.

St Mungo's Intermediate Care Project, Cedars Road Hostel, Clapham:

Such a model has been piloted in St Mungo's a 120-bed homeless hostel at Cedar Road Hostel in Clapham, South London The Homeless Intermediate Care Pilot Project started at St. Mungo's Cedars Road hostel in January 2009, with funding to run until March 2010, and utilises the services already available at the site, including some onsite GP services and trained and highly experienced hostel staff. There have been two evaluations funded by Guy's and St Thomas' Charitable Trust, a mid-point review¹¹¹ (covering January-August 2009) and a formal economic evaluation of the pilot project¹¹² (covering January-December 2009).

¹¹¹ Dorney-Smith S. *Mid-Point Review of the Homeless Intermediate Care Pilot Project. Cedars Road Hostel, Clapham. January-August 2009.* London: NHS Lambeth Community Trust & St Mungos, 2009. Accessed at: http://www.gsttcharity.org.uk/our-impact/case-studies/integrated-care-for-homeless-people/

¹¹² Hendry C & Dorney-Smith (ed). *Economic Evaluation of the Homeless Intermediate Care Pilot Project. Cedars Road Hostel, Clapham. January-December 2009.* London: NHS Lambeth Community Health, St Mungos, & Guy's & St Thomas' Charity, 2010. Accessed at:

The evaluations revealed that 34 clients had benefited from the project during the pilot project year. The morbidity burden of these clients has been extremely high: 24% have had a diagnosis of HIV, 34% have had past Hepatitis B, and 84% have active or past Hepatitis C. 83% have been intravenous drug users, 74% alcohol dependent, and 88% have had mental health problems. The clients have experienced a range of very serious conditions, including renal failure, osteomyelitis of the spine, acute bacterial endocarditis with septicemia, necrotizing fasciitis, a right jugular vein thrombosis, end-stage liver failure, MRSA infection, acute syphilis, pulmonary TB, and Wernicke's encephalopathy.

The project's main purpose is to reduce mortality and morbidity in hostel clients whilst also reducing secondary care usage. In 2008 there were 7 deaths at Cedars, and the average age of death was 38 years old. During 2009, the pilot project period, there was only one death, an outcome attributed to the Intermediate Care project. Additionally, during the pilot project year, the number of hospital admissions was 77% lower than in 2008, the number of A & E attendances was 52% lower, and the number brought to A & E by ambulance was 67% lower. The number of repeat attendances also fell by around 40%. However the length of admission has increased, probably reflecting a reduction in inappropriate and self-discharges.

The project has sought to ensure that clients are engaged or re-engaged with all the appropriate specialist services. This has been achieved, common new referrals for clients including to liver services, HIV services, chest clinics, neurology, pain management, tissue viability, the mental health team, psychology, dentistry, social work, occupational therapy, physiotherapy, palliative care and counselling services. An average of 5.4 appointments each has been attended for each client whilst they have been on the project. The did-not-attend (DNA) rate for all appointments by clients during the pilot was only 11.6% and hospital DNAs were reduced by 22%. By the mid-point review 76 escorts have been undertaken. Up to August 2009 45% of clients admitted to the project have had a detoxification undertaken, either during and/or immediately after being on Intermediate Care. Amongst achieved specific targets set for the project, 9 out of the 10 women received cervical and sexual health screening, 92% of all clients have had a Comprehensive Health Assessment, and 83% a full blood screen. 72% of clients have been confirmed immune to Hepatitis B (through blood tests) and vaccinations have been administered to non-immune clients.

The two evaluations reveal that client responses to the project have been universally positive: focus groups were undertaken with clients in order to shape the service for the future and feedback also sought from hostel staff, these findings feeding into planning for an effective on-going service.

http://www.threeboroughs.nhs.uk/document_view.php?PID=0000000252&DID=0000000000000000000217 See also: Schneller K. Intermediate care for homeless people: results of a pilot project. *Emergency Nurse* 2012 (October); 20(6): 20-24.

The economic evaluation found the pilot project to be cost neutral overall, with better health outcomes, concluding: 'This is perceived to be a major achievement for a developing service, and a demonstration that the service should be recommissioned in order to test whether the benefits can be replicated, and indeed extended'. Indeed, the project has received national recognition, as an example of innovative practice in work with vulnerable/'at-risk' groups¹¹³, was cited in the Office of the Chief Analyst's report¹¹⁴, profiled in the Guardian newspaper Society section¹¹⁵, and was awarded the 2011 Nursing Standard Community Nursing Award. Due to its success, the project was mainstreamed by community services in 2011. In early 2012 the scheme was relocated to Thames Reach's Graham House in Vauxhall. **Grade [G1, NIE]**

3.3 <u>Stand-alone intermediate care facility</u>: A stand-alone intermediate care facility might be a more amenable environment for recovery than the more hectic hostel environment and could be feasible in areas with a wide catchment such as London.

Intermediate care service in London (in planning):

Currently in the planning stage is a 20-bed intermediate care service in London that would offer 'intensive holistic health care and emotional support for those with the most complex needs, networked to other hostels that provide differing levels of primary care'¹¹⁶. On this development, the Office of the Chief Analyst has indicated: 'This would probably need to be commissioned by health commissioners and costs could be a challenge. Such a model would also need to be supported through well-developed reconnection and resettlement protocols with all boroughs of origin. The removal of the Supporting People ring fence would also help facilitate this model'.

4. Community sanctuaries and medical "respite care" approaches for the homeless with complex medical and psycho-social needs

Medical respite programmes for homeless persons have been developed by the National Health Care for the Homeless Council (HCH) in the USA¹¹⁷. Medical respite care is defined as acute and post-acute medical care for homeless persons who are too ill or frail to recover from a physical illness or

¹¹³ Department of Health. *Inclusion Health: improving primary care for socially excluded people*. London: Department of Health, 2010 (March).

¹¹⁴ Poteliakoff E. *Healthcare for single homeless people*. London: Office of the Chief Analyst, Department of Health, 2010 (March).

¹¹⁵ Gould M. The 'garden shed' where lives are being saved. *The Guardian*, 22 December 2009.

¹¹⁶ Halligan A, Hewett N, Boyce T, Gubb J. Briefing for Cabinet Office, Homeless Health Project Development Team, UCLH NHS Foundation Trust. Cited in: Office of the Chief Analyst (2010), p. 23.

¹¹⁷ National Health Care for the Homeless Council. *Medical Respite Care and Homelessness. 2011 Policy Statement.* Nashville TN: National Health Care for the Homeless Council, 2011.

injury on the streets but who are not ill enough to be in a hospital. Such care provides short-term residential care that allows homeless persons to rest while receiving medical care for acute illness or injury. It is seen as a key component within the continuum of care needed to address the needs of the homeless or those at risk of homelessness. Medical respite programmes offer hospitals an alternative to discharging patients on to the streets, thus ensuring that the medical care received in hospital is not compromised by poor and unstable living circumstances. Medical respite care is combined with housing placement services and effective case management to allow persons with complex medical and psycho-social needs to recover from an acute medical condition in a stable environment. On average, patients stay two to three weeks in a medical respite programme, the enabling services they receive comprising non-clinical services that support the delivery of basic health services and facilitate access to comprehensive patient care as well as social services. In 2009, 25% of HCH patients used enabling services (case management, benefit counselling or eligibility assistance, health education and supportive counselling, transportation, interpretation, and education regarding the appropriate use of health services) compared to 9% for all other health centre patients. One notable benefit is the reduction in future hospital admission.

In May 2000 the Health Resources and Services Administration (HRSA) provided grants to ten HCH grantees to demonstrate the impact of medical respite care on patient health. A multi-year evaluation of these medical respite programmes showed improved health outcomes and housing stability (increased access to housing and income). Upon admission, around 500 individuals (one third of the study participants) reported the hospital as their place of residence. Upon leaving the programme, just 8% of the study participants listed the hospital as their residence¹¹⁸. This study also showed increased access to welfare support (income sources such as food stamps and supplemental security income). Studies have also shown that medical respite care results in cost avoidance for hospitals and health care systems: after 3 months and 12 months post-discharge, homeless patients who were discharged to their own care¹¹⁹. Moreover, even brief stays in a medial respite programme have been found to decrease hospitalisation, reduce admissions, and reduce costs for hospitals and the health care system. These outcomes are seen to partially accrue from the time that medical respite care providers spend with patients to establish a relationship between the patient and primary care providers.

Given their impact on outcomes (reductions in hospital readmissions through quality health care and robust discharge planning programmes and the provision of a strategy to end homelessness) and cost,

¹¹⁸ Zerger S. An evaluation of the respite pilot initiative: Final report, 2006. Accessed at:

¹¹⁹ Buchanan D, Doblin B, Sai T, Garcia P. The effects of respite care for homeless patients: A cohort study. *American Journal of Public Health* 2006 (July); 96(7): 1278-1281; Kertesz S, *et al.* Post-hospital medical respite care and hospital readmission of homeless persons. *Journal of Prevention and Intervention in the Community* 2009 (April); 37(2): 129-42.

HCH is currently recommending that states support medical respite programmes. A strong argument is that medical respite services may be cost-efficient when compared with more costly inpatient stays. However, targeted funding is not available and there is a significant unmet need, while there is a substantial interest in expanding such services. HCH argue that medical respite care funding should be flexible enough to allow for varying lengths of stay among patients and not have rigid new patient target requirements. Moreover, such programmes should be underpinned by a 'whole person' philosophy, caring not just for a person's physical condition but providing linkages to long-term community care services and supports and social and family services. In the absence of appropriate discharge planning and 24-hour care management and support during transitions in care, homeless patients have no option but to remain in a hospital for an extended length of time. **Grade [G1, IE]**

This model of a package of services for people who are experiencing homelessness and in need of recuperative care is a largely US innovation, though interest has been shown in the approach by the Pathway charity.

Summary: Elements of good/promising practice in service models

Emerging elements of good practice include:

- Multi-disciplinary collaborative care is needed to meet the multiple healthcare needs of the homeless population
- Service user involvement is essential in the planning and delivery of services
- Person-centred care (as in the Care Programme Approach in mental health services) is needed
- Homeless services should provide the bridge linking hospitals and community care through hospital in-reach services
- Homeless services should include the provision of respite care (as in US and Canadian models of care)
- Coordinated health care in hospital settings by collaboration with homeless ward rounds and attending multi-agency care planning meetings
- Timely discharge planning and preparation of discharge summaries
- In areas of concentration of homeless people, specialist services should be provided to ensure that the necessary expertise is available and there is flexible service provision

There is emerging evidence that the *general practitioner and nurse-led "Pathway Homelessness"* <u>model</u> works in improving the interaction with homeless patients, enhances the patient experience, and reduces the total number of days for which beds were occupied by unscheduled admissions for homeless patients. The elements of the intervention that appear to have worked well include: the

fostering of trusting, open relationships with patients whose views are sought; prompt referrals to the team and early notifications of a potential hospital discharge; and joint working protocols enabling identification of suitable accommodation, preventing delayed discharge, a return to street homelessness, and a reduction in recurrent admissions. The Pathway charity is promoting this approach by developing a team of 'care navigators' (people with experience of homelessness who provide peer support on the ward and for a time after discharge), recruited from voluntary sector homeless organisations but with honorary hospital contracts. A two centre RCT of the Pathway approach funded by NIHR is under way at the Royal London Hospital and Brighton and Sussex University Hospital.

Implications for further research/evaluation

- 1. The Faculty for Homeless Health has published 'Standards for commissioners and service providers'¹²⁰. The document presents generic standards for all services, followed by specific standard sets addressing primary care, migrant health, community mental health services, personality disorder services, psychology, counselling, prison medical services, dentistry, podiatry, substance misuse services, and respite care, noting: 'The Faculty for Homeless Health will offer clinical governance oversight for any member organisation that requests it, and evaluate services against these standards'. The utility of these published standards as current best practice provides a reference set against which homeless services can be evaluated.
- 2. The Office of the Chief Analyst has reported a lack of research evidence on the potential for improved primary care to reduce secondary health care costs and improve health outcomes. Research is needed to assess the overall effect on costs and outcomes of improved primary care models. This would need to assess the higher costs of providing specialist services for homeless people compared with mainstream practice, the likely improved outcomes, and the impact of these specialist services on secondary care use (including possibly higher utilisation rates arising from increased referrals for previously undiagnosed conditions).

¹²⁰ The Faculty for Homeless Health (ed Nigel Hewett). *Standards for commissioners and service providers*. (version 1.0). London: College of Medicine & Pathway London. 2011 (May). Accessed at: <u>http://www.londonpathway.org.uk/uploads/homeless_health_standards.pdf</u>. See also forthcoming (May 2013) document on medical respite standards.

- 3. Many different delivery models have been described in the literature for specialist services in treating homeless persons. They include outreach, 'in-reach' into hostels, use of personal budgets, provision of peer support and mentoring, the role of the single key worker, the utilisation of pathway approaches, etc. Most of these different delivery models for specialist services require evaluation.
- 4. There is scope to pilot different service models for hospital discharge that would provide better integration between health and housing agencies and feed into the current Department of Health work stream on improving practices for homeless people.
- 5. A number of models of specialist homeless intermediate care have been described in the literature (e.g. the 'hub model' based at one hostel vs. 'diluted/group model' across 2-3 hostels). Research on these models of specialist homeless intermediate care is needed to establish which of the models is most appropriate for differing geographical areas, with varying sizes of homeless populations, the extent of existing services, levels of deprivation, and social exclusion.

3.4 Sex workers

Definition

Sex workers are a heterogeneous group, encompassing street sex workers, off-street sex workers, and female, male and transgendered/transexual ('trans') sex workers, the last being a largely migrant group. From a health services or epidemiological perspective, an important component of the definition is that the motive for sex is money.

3.4.1 Policies

The Department of Health's latest framework document for improving sexual health acknowledges that some sex workers are at higher risk of poor sexual health outcomes¹²¹. Their sexual health needs may be also detrimentally affected by experiencing vulnerabilities such as violence, rape and sexual assault, homelessness, and drug and alcohol problems. Specialist services are needed because of the barriers to accessing mainstream services experienced by sex workers. These may encompass wariness around disclosure to health professionals because of the legal framework around sex working; fear of stigma and judgemental attitudes; difficulties in accessing standard opening hours, especially those leading chaotic lives affected by drug and alcohol abuse; and access to services might be controlled by others, particularly sex workers who are being trafficked, coerced, or 'pimped'.

Moreover, specialist services should be comprehensive, providing screening and treatment, contraception, vaccinations, health promotion, and access to support for violence and abuse and ways to leave sex working. The framework document indicates that for young persons under 16 identified at being at risk of sexual exploitation (including commercial sex work), an immediate referral should be made to children's social care services and to the police.

As part of its policy of ending violence against women and girls in the UK, in December 2011 the Home Office announced a 12-month national pilot scheme to help protect sex workers from violent and abusive individuals¹²². This will bring together locally run 'Ugly Mugs' schemes which encourage sex workers to report incidents of violence: perpetrators' details are shared with other sex workers to improve safety and, if the victim consents, can be passed to the police. The Home Office has provided around £108,000 to establish a national online network to collate and distribute information between 'Ugly Mugs' schemes in local areas. The initiative is being run by the UK Network of Sex Work Projects and it will also measure how effective it is in the reporting of crimes,

¹²¹ Department of Health. A Framework for Sexual Health Improvement in England. London: Department of Health, 2013 (March).

¹²² Home Office. Pilot to improve safety of workers. 17 December 2011. Accessed at: https://www.gov.uk/government/news/pilot-to-improve-safety-of-workers

early data yielding variable outcomes. Between 15th July 2012 and February 2013, for example, 42 serious incidents were reported in London to National Ugly Mugs (data is not available at borough level). In 11 of these incidents (26.2%) the victims were also willing to report to the police¹²³. By contrast 70% of all NUM referrals in Merseyside also report to the police, where good practice has been embedded in services.

The policy initiative to close down brothels in the run up to the 2012 Olympic Games was controversial. Scotland Yard's human exploitation and organised crime command (SCD9), launched in April 2010, established a team to tackle vice-related crime in the five Olympic host boroughs: Waltham Forest, Hackney, Tower Hamlets, Newham and Greenwich. Figures released to Parliament by the Home Office showed that SCD9 carried out 80 brothel raids between January to August 2010 in the five boroughs. There were a further 20 raids in Westminster and 13 in Camden, the two boroughs that were expected to play host to the majority of tourists coming to the capital for the 2012 Olympic Games. In contrast, in the remaining 25 London boroughs, there were just 29 raids over the same period. In one borough alone (Newham) it was reported that a total of 80 brothels had been closed¹²⁴. There has been criticism on the grounds of lack of care for the sex workers and overreaction by the police: '...the report authors got the sense that in this operation there was no consideration to what would happen to the vulnerable women in the brothels or any follow up to what had happened to them'. The probation union, Napo, argued that it would result in driving the trade underground, exposing sex workers to more dangerous circumstances or forcing them into street work. There has also been a loss of contact with services. Open Doors, a health agency for sex workers in East London, reported that there had been a significant displacement of sex workers throughout Newham, with a decline of 25% in referrals to health clinics since the previous year. Women on the Streets (WOTS) also reported that during and after the Olympic Games they had seen a three-quarters drop in the number of women using their service.

In addition there had been earlier high-profile Metropolitan police operations in 2006 and 2007, Pentameter 1 and 2, focusing on trafficking, resulted in 1,337 premises being raided. This led to 232 arrests under Pentameter 1 and 528 under Pentameter 2. More than 250 women were removed and 37 took up services from support projects.

Many local authorities have been active in the development of policies to address both inequalities in health experienced by sex workers and enforcement, in some cases involving comprehensive reviews. These include the two Inclusion Health's Scrutiny Development Area Projects that focus on street

¹²³ Westminster Sex Worker Task Force (2013) citing data provided by Alec Bryce, Co-ordinator of National Ugly Mugs (February 2013).

¹²⁴ Draft Report of the Crime and Disorder Scrutiny Commission into Street Prostitution in Newham. December 2012.

workers. The London Borough of Newham has undertaken a comprehensive review of services in an endeavour to develop a more joined-up holistic policy which has involved testing the Centre for Public Scrutiny's return on investment model. Lambeth Council has recently published its violence against women and girls strategy¹²⁵.

Policy has also been developed and shaped by agencies representing the sex worker population and sex worker projects. The UK Network of Sex Work Projects, a national voluntary sector agency, has produced Good Practice Guidance Working with Migrant Sex Workers, including guidance on legal issues related to sex work and good practice for health professionals working with migrant sex workers, as well as a substantial body of more general guidance for professionals working with sex workers. The UK Network's Directory of Services for Sex Workers provides information on local services including those focusing on migrant sex workers. There is also a national directory of sex work projects that includes contact details and a brief description of the services offered¹²⁶.

3.4.2 Accessing primary care

There is a range of evidence that indicates that sex workers experience difficulties in accessing primary care and other health services.

- A number of sources report low registration with GPs. For example, Newham Public Health found that indoor sex workers in the borough were not registered with GPs¹²⁷. Jeal and Salisbury (2004)¹²⁸ reported that 83% (59/71) of female street-based sex workers in central Bristol were registered with a GP. However, 80% (57/71) of this sample reported difficulties in attending GP surgeries, the commonest difficulties being waiting for available appointments, difficulty in keeping appointments made, and waiting with other patients.
- This study showed that the most common source of care over a 12 month period was the GP (82% using a GP compared with 41% A & E, 34% STI clinic, 30% inpatient clinic, and 24% outpatient clinic); the total number of contacts for GP (n=604) outnumbered other services (range 42-73) 8- to 14-fold.

¹²⁵ Safer Lambeth Partnership. *Safer Lambeth's Violence Against Women and Girls Strategy*, 2011-14. Lambeth: Safer Lambeth Partnership, 2011.

¹²⁶ See: http://www.uknswp.org/projects/

¹²⁷ Newham Public Health. *Newham Sexual Health Needs Assessment – Sex Workers 2012/13*. 2012.

¹²⁸ Jeal N, Salisbury C. Self-reported experiences on health services among female street-based prostitutes: a cross sectional survey. *British Journal of General Practice* 2004;

- In an interview study of 50 street-based sex workers in Lausanne, Switzerland¹²⁹, a total of 36 participants (36/50, 72%) had consulted a doctor in the preceding year, generating 54 consultations including 17 check-ups (though only 11% in general practice). 26% of the consultations were in the Lausanne Emergency Department.
- In a multi-method study conducted with female sex workers in Laval, Quebec, the questionnaire survey (n=201) found that over 80% had consulted health professional during the preceding 12 months, including 52.7% with a medical clinic, 50.7% with a local community service centre, and 26.4% with a hospital emergency service¹³⁰.
- In a small sample of 20 women engaged in opportunistic or survival sex work in Tyne and Wear, 16/19 or 84% were registered with a GP, although half (10/20) reported difficulties in keeping appointments¹³¹. In an earlier study of 86 sex workers in Newcastle, Gateshead, Sunderland, South Tyneside, and North Tyneside, 79% (68/86) had a GP but only 46.5% (40/86) a dentist¹³².
- Amongst 303 female sex workers in Christchurch, New Zealand, most (250, 82.8%) were registered with a GP¹³³.
- GPs and other services do not always record sex worker status¹³⁴, though Read Codes are now available.
- There is some evidence to suggest that many sex workers do not disclose their work to their GP¹³⁵; nearly two-thirds of those registered with a GP (36/59) in the Jeal and Salisbury (2004) study had not disclosed that they were involved in sex work, which may result in lack of appropriate care. Only about half of the sex workers in Christchurch registered with a GP disclosed they were sex workers. Of the 135 women who used their own general practitioner for sexual health checks, 62% disclosed they were sex workers. Amongst the 50 street sex workers interviewed in Lausanne, depending on the service consulted, participants disclosed

¹²⁹ Katharine Elizabeth Anna Darling, Elodie Gloor, Anne Ansermet-Pagot, Paul Vaucher, Sophie Durieux-Paillard, Patrick Bodenmann, Matthias Cavassini. Suboptimal access to primary healthcare among street-based sex workers in southwest Switzerland *Postgrad Med J* doi:10.1136/postgradmedi-2012-131001.

sex workers in southwest Switzerland *Postgrad Med J* doi:10.1136/postgradmedj-2012-131001. ¹³⁰ Nguyen M-N, Venne T, Rodrigues I, & Jacques J. Why and According to What Consultation Profiles Do Female Sex Workers Consult Health Care Professionals? A Study Conducted in Laval, Quebec. *Health Care for Women International* 2008; 29: 165-182.

¹³¹ Peer Research Team. *Exploring the Lives of Sex Workers in Tyne and Wear*. 2013 (January). Accessed at: http://www.nr-foundation.org.uk/wp-content/uploads/2013/01/PEER_finalreport_full_v1_2.pdf

 ¹³² The Voices Heard Group, Laura Seebohm, and Sharon Smiles. *Hidden for Survival. Peer Research into the lives of sex workers within Newcastle, Gateshead, Sunderland, South Tyneside, and North Tyneside. Research Study TC-02*. Counted4, Tyneside Cyrenians, & Scarman Trust, 2008 (February).
 ¹³³ Plumridge L, Abel G. services and information utilised by female sex workers for sexual and physical safety.

¹³³ Plumridge L, Abel G. services and information utilised by female sex workers for sexual and physical safety. *New Zealand Medical Journal* 2000; 113(1117): 370-72.

¹³⁴ Draft Report of the Crime and Disorder Scrutiny Commission into Street Prostitution in Newham. December 2012. See also: Westminster Sex Worker Task Group. *Violence Faced by Sex Workers in Westminster*. Recommendations Report. 2013.

¹³⁵ GPs to champion vulnerable groups: Accessed at <u>http://www.gponline.com/News/article/1043910/GPs-champion-vulnerable-groups/;</u> Jeal & Salisbury (2004), ibid.; Westminster Sex Worker Task Group. *Violence Faced by Sex Workers in Westminster*. Recommendations Report. 2013.

their profession 40%-64% of the time¹³⁶. In the multi-method study conducted with female sex workers in Laval, Quebec, the small interview study found that only half of the respondents who consulted their family physician disclosed their occupation¹³⁷.

- In a small sample of female street-based sex workers in Bournemouth, only 65% (11/17) were registered with dental services¹³⁸.
- . The nocturnal lifestyle of some sex workers - working through the night selling sex and sleeping during the day - make it difficult for them to use services during 9-5 opening hours¹³⁹.
- The chaotic lifestyle of street sex workers (including use of illicit drugs and alcohol) makes it difficult for them to organise and keep appointments.
- A distrust of services has been reported, perhaps based on bad experiences. For example, one woman described herself as being treated 'not very fairly' by services offered by the council and NHS¹⁴⁰.
- Some sex workers experience stigma from those running services for being involved in sex work. In the Jeal and Salisbury (2004) study, 45% (32/71) reported that fear of being judged by staff made attending the GP surgery difficult.
- Homelessness, no ID, and no recourse to public funds may make access to services difficult¹⁴¹.
- Amongst migrant sex workers working off-street, the main difficulties faced in accessing health and social services was reported to be language difficulties, limited knowledge about how to access services, irregular and undocumented legal status, and the time pressure of work with long hours¹⁴².

In addition, sex workers make limited use of preventive health care. In the Bristol study:

Only 46% (33/71) had been screened for sexually transmitted infection in the previous year

¹⁴² Institute for the Study of European Transformation. Evaluation of the Services Offered to Migrants in Haringev and Enfield by SHOC. Final Report. London: London Metropolitan University, 2011 (February).

¹³⁶Darling, Gloor, et al. (2012), ibid.

¹³⁷ Nguyen M-N, Venne T, Rodrigues I, & Jacques J. Why and According to What Consultation Profiles Do Female Sex Workers Consult Health Care Professionals? A Study Conducted in Laval, Quebec. Health Care for Women International 2008; 29: 165-182.

¹³⁸ Bournemouth Alcohol and Drug service User Forum & Links. Sex Workers Health Needs. December 2012. Accessed at:

http://www.makesachange.org.uk/cms/site/docs/SEX%20WORKERS%20HEALTH%20NEEDS%20REPORT.

pdf ¹³⁹ Safe Exit. 'A Template for a Multi-Agency Approach to Tackling Street-Based Prostitution' (cited by Newham Crime & Disorder Scrutiny Commission, 2012).

¹⁴⁰ Newham Crime and Disorder Scrutiny Commission, 2012, citing 'Response to small survey of women involved in street prostitution carried out in December 2012 through the help of DASL'.

¹⁴¹ Open Doors presentation to Newham Crime and Disorder Scrutiny Commission, 'Understanding and meeting the needs of street-based sex workers', 20th March 2012.

- Only 24% (17/71) were vaccinated against hepatitis B, a national recommendation for sex workers
- Only 38% (25/65) had had cervical smears according to screening guidelines
- While pregnant with their last child, only 30% (14/47) booked in the first trimester and attended all antenatal appointments, with 13% (6/47) receiving no antenatal care until admitted in labour.

Sex worker outreach projects have also reported that migrant sex workers find it difficult to access timely and free terminations of pregnancy¹⁴³.

Service/Organisational Interventions: Introduction

Services for sex workers need to cater for the different drivers, profiles and risk exposures of those involved in sex work as they are not a homogeneous group. Those on street are driven by the drug economy, the work takes place mainly at night, and these sex workers tend to have much poorer health than those in the off street industry. Night-time outreach sessions are likely to be important or clinic facilities close to where they operate. Off street sex workers are a more hidden population, the majority of whom are migrants, some of whom are irregular (visa overstayers, illegal entrants, etc.) and often fear deportation. Language barriers may exclude them from accessing services and they may have a poor understanding of services available to them. They may also be subject to exploitation and coercion, including vulnerability due to abusive or exploiting partners and pimps. In the London Borough of Newham, off-street sex workers (400-500) outnumbered street sex workers (67) 6- to 7fold. Transgendered/transexual ('trans') sex workers are a largely migrant group, with significant proportions on student visas or selling sex to pay for gender re-assignment surgery. Some sex work projects particularly target this group and clinics need to be sensitive to the trans person's gender identity to avoid stigmatisation. People who have been trafficked and are involved in sex work are victims of crime and there is a national referral mechanism. Some services have acquired specific expertise around supporting this client group and access to women only services or women only clinics may be necessary from a safety perspective. Finally, sexual exploitation may take place amongst looked-after children and children and young people on a child protection plan.

There are a wide range of good/promising practice interventions designed to improve the health of sex workers and facilitate access to primary care and other services. They vary in scale from single GP practice interventions to borough-wide, multiagency partnerships with a broader set of objectives related to law enforcement and exit from sex work. They also vary in terms of how services are

¹⁴³ Feldman, 2012.

delivered. Outreach services may be particularly important for street sex workers because of the nighttime hours they work and for indoor sex workers because of the hidden nature of this work.

Interventions to increase GP registration

No interventions have been identified that have been set up specifically to facilitate the registration of sex workers with GPs. While local enhanced schemes have been established with this aim for some of the other vulnerable groups, this does not appear to be the case with sex workers. However, some local authorities and statutory health bodies have put in place alternative arrangements. In the London Borough of Newham the Transitional Primary Care Team provides GP registration for those who have been refused GP registration elsewhere. This ensures that the borough's transitional and no fixed abode population (refugees, asylum seekers, students, homeless, and Gypsy/Traveller communities) can access a GP without having to give an address, passport, etc. They register sex workers on an ad hoc basis and have only recently started recording such information¹⁴⁴. A similar arrangement has been adopted in Hackney, where the Transitional Primary Care Service (based at the Greenhouse Practice in Hackney) focuses on '...people who routinely spend the night outdoors, socially excluded patients including hostel dwellers and sex industry workers, and other marginalised groups referred by partner organisations'¹⁴⁵. Both services come under the umbrella of East London NHS Foundation Trust. In addition both statutory organisations (like Open Doors: see below) and voluntary organisations (such as Project:London) have sought to increase GP registration as part of wider sex worker intervention projects. For example, Sex Workers around Northamptonshire (SWAN: see below) achieved an increase in registration of sex workers with GPs (achieving a 90% level by the start of 2009)¹⁴⁶. Grade [G4]

Dedicated/specialist clinics and practices

A few dedicated clinics have been set up to cater for the needs of sex workers. Some of these provide services exclusively to sex workers while others cater for other vulnerable groups as well. Dedicated clinics tend to be located in areas with significant numbers of sex workers and frequently offer a range of health, social care, and support services.

¹⁴⁴ Draft Report of the Crime and Disorder Scrutiny Commission into Street Prostitution in Newham. December 2012.

¹⁴⁵ https://www.eastlondon.nhs.uk/our_services/dept_transitional_primary_care_service_hackney.asp

¹⁴⁶ Department of Health. *Transforming Community Services & World Class Commissioning: Resource Pack for Commissioners of Community Services*. London: Department of Health, 2009.

Edinburgh Access Practice is a medical practice staffed by GPs, practice nurses, community psychiatry nurses, a substance misuse team, dentist, and podiatry. It assists individuals unable to access mainstream Primary Care Services, particularly homeless persons, asylum-seekers and exprisoners. In 2011 it expanded its remit to include street sex workers. It provides a nurse led drop in clinic on Friday afternoons, held at Leith Community Treatment Centre Outpatient Department. The clinic focuses on general health concerns such as: wound management, long term condition management, minor illness, BBV screening, vaccinations for Hepatitis A& B, pregnancy testing and contraception advice. Eligibility criteria are: individuals unable to register with mainstream medical practice. There is a self-referral process and initial health assessment is carried out on registration. **Grade [G4]**

Armistead Street Night Time Health Clinic, Liverpool¹⁴⁷

This service is cited as an example of effective practice in holistic approaches to health needs. The intervention comprises a night time primary care clinic in partnership with a general practice located in an area where street sex working takes place. Those who use the service can see a GP for general health needs, mental health needs, have an assessment for drug treatment, and access sexual health services. Staff will also act as advocates for service users to access primary care and hospital services, referring and accompanying service users if required. Armistead have worked closely with Accident and Emergency (A & E) managers and staff at the Royal Liverpool Hospital to address barriers to accessing A & E, including: A & E staff accompanying outreach, a range of training delivered to A & E doctors, nurses, and reception personnel by Armistead staff, and raising awareness about the support needs of sex workers. No evaluations of this clinic have been located. **Grade [G4]**

Doctors of the World and Project:London¹⁴⁸

Doctors of the World UK (DOW UK), part of the Médecins du Monde network, was established in January 1998 and is an international aid organisation that provides medical care and gives a voice to vulnerable people all over the world. In the UK Doctors of the World runs Project:London where it helps some of the capital's most vulnerable groups, including victims of torture and people fleeing violence, pregnant mothers unable to access antenatal care, and babies in need of basic immunisations. Its volunteer doctors, nurses and support workers provide information, advice and practical assistance on how to access mainstream health services. Its clinic also provides basic

content/uploads/uknswpsubHOrevlocprac21stMar2011FIN-1.pdf

¹⁴⁷ See: Campbell R, & Pitcher J. *UKNSWP Submission to: "Home Office Review of Local Effective Practice*". UK Network of Sex Work Projects. 2011 (March). Accessed at: http://www.uknswp.org/wp-

¹⁴⁸ See: http://www.doctorsoftheworld.org.uk/projectlondon/projectlondonpartners.asp
healthcare in the interim period until its service users are fully integrated into NHS and other support services.

All of its health professionals are registered with the General Medical Council for doctors, or the Nursing and Midwifery Council for nurses. Most of the doctors and nurses are currently working in the NHS and choose to volunteer for Project:London in their spare time. The support workers come from different walks of life, including medical students and others who work in administration, IT or public health. All the volunteers have received specific training to prepare them to work for Project:London. With respect to sex workers, one of Project:London's partners is CLASH (Central London Action for Street Health) and it attends CLASH's Friday sexual health clinic to facilitate access of CLASH service users to mainstream NHS services, including help with GP registration and assistance in claiming help with health costs. No evaluations of this service have been identified. **Grade [G4]**

Specialist outreach and sexual health services for sex workers

There are eight specialist outreach and sexual health services for sex workers across London, providing services from a public health/harm reduction basis. Some have been established for over twenty years and have seen thousands of sex workers. They are all well-coordinated and have been cited as good practice examples. These services are:

- SHOC North London
- Praed Street Central and West London
- Working Men's Project Central and West London
- SWISH South West London
- CLASH Central and North London
- Open Doors East London
- Spires South London
- Surrey NHS¹⁴⁹ Outreach Team

There are some similar services outside London. Some case studies of London services are described below:

<u>SHOC</u> (Sexual Health On Call) is an outreach and support service for street-based and off-street (brothels, saunas, massage centres, etc.) sex workers in the boroughs of Haringey and Enfield. The major part of the funding is for targeted services for street sex workers: two street outreach sessions per week and two daytime drop-ins, where a range of support and interventions are delivered. While

¹⁴⁹ Now part of Virgin Health.

the majority of street sex workers contacted in outreach are UK nationals, increased numbers of migrant women have been encountered in the off street work. By 2008/09 the majority of service users seen were migrants: of 169 sex workers in around 20 premises, at least 122 (72%) were non-UK nationals¹⁵⁰. In 2009-10 this proportion increased to 75%¹⁵¹ (Eastern European nationalities constituting the largest proportion of off street migrant sex workers, the main nationality being Romanian, but with an increase in Hungarian and Polish women). In 2009 services were increased for migrant sex workers following the award of Migrants Impact Fund funding. This included provision for a bilingual worker role: 2 bilingual workers were appointed whose key role was to address language and cultural barriers to service access by migrant sex workers, enabling outreach to be increased to 2 sessions per week. During off-street outreach SHOC offers a range of services, including free condoms and lubricant, 'ugly mug' newsletters, and information about relevant referral services (drug/alcohol abuse, termination of pregnancy, etc.). The service is delivered to 20 premises in Haringey and Enfield.

SHOC also runs a sexual health clinic for sex workers two times per week, offering sexual health screening and treatment, family planning, HIV and Hepatitis testing and vaccination, and pregnancy testing. The MIF funding enabled SHOC to increase its services from one clinic a week to two, with a bilingual worker attending one of the clinics. An evaluation of services offered by SHOC to migrant sex workers in these two boroughs¹⁵² found that since the introduction of the second clinic and the bilingual workers in 2009 there had been a marked increase in migrants accessing clinic services, these sex workers now being more than 50% of clinic attendances. The bilingual worker role enabled enhanced trust and communication to emerge and enabled migrant service users better able to identify their needs. However, an English language service offered by a sex workers attracted a very poor attendance. **Grade [G2, IE]**

<u>The Praed Street project</u> is a sexual health and support service for women who work, have worked or are associated with any part of the sex industry within London. Launched in 1985, it is based at St Mary's Hospital in Paddington (part of Imperial College Healthcare NHS Trust) and was the UK's first dedicated sexual health service for female sex workers. There is currently an average of 3000 attendances per year and contact with 800 individuals. The clinic provides: confidential testing and check-ups for sexually transmitted infections including HIV (counselling is also offered with HIV testing); vaccinations against hepatitis A and B; cervical smears; free condoms and some contraception, including the pill contraceptive injection (Depo-Provera) and the contraceptive

¹⁵⁰ SHOC. Annual Report 2008-09. London: SHOC, 2009.

¹⁵¹ SHOC. Annual Report 2009-10. London: SHOC, 2010.

¹⁵² Institute for the Study of European Transformation. *Evaluation of the Services Offered to Migrants in Haringey and Enfield by SHOC. Final Report.* London: London Metropolitan University, 2011 (February).

implant; free emergency contraception; appropriate advice on sexual health at work and home, information about infections and how to prevent them; and information about safer sex, broken condoms, and condom use. The clinic offers advance appointments and same day appointment clinic. There is a drop in and support service three afternoons a week held in an informal setting away from the clinic. The project provides outreach services to working flats within the local area of Westminster and Kensington and can offer some sexual health check-ups and tests in the person's flat or sauna. The outreach team is currently visiting 47 flats.

The Cabinet Office's Social Exclusion Task Force identified the intervention as 'promising practice'¹⁵³, noting in particular: the 'whole person' and family approach to care; the informal drop-in service; outreach to engage new clients and re-engage existing clients; being an NHS service and on a hospital site, conferring staff credibility; personalisation as a key element of building trusting relationships with clients; partnership working (the project working with the TB team in St Mary's, the Westminster drug project, the Caravan, Poppy Project, Salvation Army, and further education services); and inbuilt service evaluation (outcomes are measured using clinical targets, in line with national sexual health targets, e.g. ensuring the clinic is full, maintaining low infection levels, and providing comprehensive follow-up care (treatment, completing medication, contact tracing to minimise risk of spreading infection)). **Grade [G4]**

CLASH¹⁵⁴

CLASH (Central London Action on Street Health) is a Camden Primary Care Trust HIV prevention and outreach project that works with male and female sex workers, homeless people, drug users and gay and bisexual men regarding HIV and sexual health in central London. It is funded by Camden, Westminster, and Islington PCTs and is currently hosted at St Mary's Hospital. CLASH provides a direct referral route to GUM clinics and other relevant support services. Much of the CLASH team's health promotion work is conducted in community settings and through outreach. As well as conducting outreach in flats, saunas and bars, CLASH runs two sexual health clinics for female sex workers. Condom distribution is also provided by the CLASH team.

Outreach has been a key feature of CLASH's activity through use of the Healthbus. With respect to men who have sex with men (including sex workers), for example, CLASH has used the Healthbus for over 120 Sessions and made an estimated 1000 contacts between March and December 2005. 645

¹⁵³ Cabinet Office Social Exclusion Task Force & Department of Health. *Inclusion Health Evidence Pack*. Department of Health & Cabinet Office, 2010 (March). Accessed at:

http://webarchive.nationalarchives.gov.uk/+/http://www.cabinetoffice.gov.uk/media/346574/inclusion-health-evidencepack.pdf

¹⁵⁴ Camden NHS Primary Care Trust. Sexual Health and HIV Strategy (2007-2012). Accessed at: camden.gov.uk/ccm/cms-service/download/asset/?asset_id...

of these contacts were made in Old Compton Street ad 355 in Hampstead Heath. Occasionally CLASH used the Healthbus in conjunction with the Metropolitan Police to foster better relations between them and users of Public Sex Environments. As noted (above) Project:London attends the weekly sexual health clinic to facilitate CLASH users' access to mainstream NHS services, including help with GP registration. **Grade [G4]**

Open Doors, London¹⁵⁵

Open Doors London offers community sexual health services, including male and female partners' work, specialist advice, street outreach in Hackney, indoor outreach in East London (Newham, Tower Hamlet, and Hackney), and Open Door Clinics at Ambrose King Centre, Royal London Hospital, St Bartholomews Hospital, Homerton University Hospital, and Newham University Hospital. Open Doors also provides a range of drug services targeted at female street sex workers, including harm reduction information, supplies and advice, and fast track into drug prescribing and primary care. They offer specialist support from a drugs worker (delivered in partnership with the local Drug Action Team) to the male partners of street based sex workers, in recognition that for some women involved in street sex work their drug use and sex working is shaped by their partners' problematic drug use. According to a recent report, Open Doors had seen 510 off-street sex worker clients in Newham between April 2010 and February 2011, this amounting to 72% of all the off-street sex workers seen by Open Doors from the three boroughs (Newham, Hackney, and Tower Hamlets) where it works. This number fell to 396 in Newham in 2011/12, a drop that was seen as a consequence of police action in closing down brothels in the run up to the Olympic Games.

While no evaluations have been identified, a 2008 report¹⁵⁶ is available on the local sex worker outreach project at Homerton University Hospital, which in July 2006 developed the weekly drop-in for street-based sex workers. From the drop-in, sex workers were fast tracked to attend a range of dedicated health services, including the GUM clinic. Between 1 July 2006 and 31 January 2007 the outreach team made contact with 120 street-based sex workers in the borough. 40 of these attended the drop-in and 25 attended the GU clinic. While female sex workers have recently been reported to experience declining incidence of sexually transmitted infections, this observational study found that 8 had tuberculosis, 7 were pregnant, 6 were HIV positive, 12 had positive syphilis serology, and a further 17 STIs were identified. There were frequent reports of recent recreational drug use,

¹⁵⁵ See: Campbell R, & Pitcher J. *UKNSWP Submission to: "Home Office Review of Local Effective Practice"*. UK Network of Sex Work Projects. 2011 (March). Accessed at: <u>http://www.uknswp.org/wp-content/uploads/uknswpsubHOrevlocprac21stMar2011FIN-1.pdf</u>; http://www.opendoors.nhs.uk/

¹⁵⁶ Creighton S, Tariq S, Perry G. Sexually transmitted infections among UK street-based sex workers.*Sex Transm Infect*. 2008 Feb; 84(1):32-3. Epub 2007 Sep 27.

unprotected sex with clients, no reliable contraception, and considerable amounts of other physical ill health in this group, with frequently reported risky sexual behaviour. Thus, this study demonstrated the need for such targeted development work to meet these women's multifactorial needs.

A 2009 report on residents' views of health and health services in Hackney and The City – including 10 sex workers accessed through Open Doors – provides indicative evidence of the efficacy of this service¹⁵⁷. The report commented: 'On the whole, the women were positive about NHS services in Hackney and were generally satisfied. It is worth noting that this may be heavily influenced by their interaction with the Open Doors service, which was very highly thought-of. The service can fast-track women through the NHS, for sexual health checks for example, and also helps them to register with a GP or access other services'. With respect to sexual health services, for example, one of the female sex workers commented: 'They're really good. The waiting time is a long time, but through Open Doors we've got a quick process where we go through [...] and we get dealt with, not straightaway but quicker and plus they're very friendly, they don't judge us'. [Grade G3, NIE]

One-stop shop sexual health service in a UK female prison

From April 2006 the Genitourinary Medicine Service was transferred from the Home Office to the NHS at this female prison to give prisoners access to the same quality of health care as the general public, the main aim being to develop a one stop sexual health shop¹⁵⁸. Review of the service at one year along with retrospective case note review from May 2006 to August 2007 was undertaken. While only 6% of the 545 new patients seen were sex workers, history of substance abuse, IVDU, sexual abuse, sex worker and past history of hepatitis C virus and chlamydia in the full sample were 86%, 41%,12%, 17% and 24%, respectively. The uptake rate for both STI screen (87%) and blood-borne viruses (BBVs) testing (69.3%) was high. STIs were diagnosed in 19.6% of patients. Prevalence rates were: Trichomonas vaginalis (TV) 8.2%, chlamydia 5.3%, gonorrhoea 0.2%, genital warts 5.3%, HIV 0.8%, hepatitis C virus 12% and hepatitis B virus 11%. The uptake rate for first dose hepatitis B vaccination and cervical cytology were 70% and 92% respectively. 36 accessed contraceptive services. This study demonstrated that provision of a one stop shop in a female prison is feasible and practical, with prevention methods targeting this population needing to be intensified. **Grade [G3, IE]**

¹⁵⁷ Ipsos MORI. *Residents' views of health and health services in Hackney and The City.* 2009 (May). Accessed at: xa.yimg.com/.../MORI_CityHackney_2009_final_report_28_7_09.d...

¹⁵⁸ Mahto M, Zia S. Measuring the gap: from Home Office to the National Health Service in the provision of a one-stop shop sexual health service in a female prison in the UK. *Int J STD AIDS*. 2008 Sep;19(9): 586-9. doi: 10.1258/ijsa.2008.008051.

Drug and alcohol interventions

Women on the Streets (WOTS) is a drop-in service run by Drug and Alcohol Services for London (DASL) for street workers in Newham. Newham Council through its Drug Action Team commissioned the Women on the Streets pilot in 2006. This was a drop-in service for street workers, employing 8 staff from 5 different organisations, which ran twice a week. The staff included a nurse and an outreach worker. The staff helped the women with needs from drug abuse to domestic violence and sexual health. In the face of budget constraints (the WOTS service was costing £50,000 a year), the Council's Drug Action Team had to end its funding of WOTS in 2011. A downsized service continued to be run by DASL but with only one staff member and limited funds ($\pounds 9,595$ for 2011/12) but only once a week for an hour. In this year the reduced service still saw 70 women, demonstrating the need for the service. The WOTS Project will recommence from April 8th 2013 following support from Newham Strategic Commissioning. Some notable benefits are that it is an out-of-hours service and benefiting from the range of health interventions offered. It provides a safe place to rest and talk; needle exchange; condoms; food; shower facilities; clothes washing facilities, and personal alarms. WOTS also gives support and advice on harm minimisation/reduction and helps service users into treatment if required. While no evaluation is available, quotes from service users indicate a much valued service. Grade [G4]

Holistic interventions, including exit from sex work

<u>Base75</u> is a Glasgow support and health care service to women involved in sex work and focuses on preventative healthcare. It is staffed by a group of resource workers from a social work department with a nurse on duty six nights a week and in addition doctors five nights per week. A consultant gynaecologist from Sandyford is present one morning a week. It is linked into the whole Sandyford and Routes out of Prostitution Initiatives. Services include needle exchange, free condoms, safer sex advice, treatment for acute medical conditions, screening tests, cervical smears, contraception, vaccinations (hepatitis B, rubella, tetanus), and referral to other agencies as necessary. Outreach staff make contact with women working in flats and saunas. The Base is run in partnership with Glasgow Community Safety Services. **Grade [G4]**

The <u>Sex Workers Around Northampton (SWAN) programme</u> had its origins in a community crime and anti-social behaviour initiative which found that street work and drugs were key issues affecting the Spring Borough part of Northampton. A multiagency partnership (PCT, Drugs and Alcohol Team, Police, GP service, Probation, Housing, Borough and County Council) was established to provide a range of services to assist women to exit sex work. A multiagency approach was regarded as essential because of the need to draw on a wide range of skills to meet the needs of the target clients.

The overarching aim of the service is to provide safe supported and sustainable opportunities for sex workers to exit sex work, thereby improving the life chances of all those involved. The partnership also works to improve the quality of life for the local community affected by sex work and contributes to the reduction of crime caused by illegal drugs and antisocial behaviour. The approaches or elements of practice delivered from a range of agencies (PCT, Drugs & Alcohol Team, GP service, Probation, Housing) include¹⁵⁹:

- Evening outreach to street sex working areas
- Targeted outreach to indoor sex working establishments
- One to one appointments (including enforceable criminal justice appointments)
- Dedicated drop in times
- Flexible contact at the dedicated centre
- Housing support and direct accommodation
- Probation support
- Fast drug treatment (48 hours turnover)
- Practical assistance (e.g. sexual health materials, showers, washing facilities, needle exchange)

Some evaluative information is available:

- At the start of the programme there were 200 street sex workers providing a 24 hour service. By the start of 2009 this had fallen to around 20 active street sex workers working only at night.
- Reduction in crime within the local community
- Increase in the number of sex workers registered with a GP (to 90% at the start of 2009)
- Increased number of sex workers accessing substance treatment
- Increased number of sex workers in safe, sustainable housing
- Increased access to health screening
- Reduced instances of sexually transmitted infections and blood borne viruses
- Increasing number of sex workers retained on probation orders
- Decreasing levels of crime in sex working population (reduction from £16 million drug user per annum at start of programme to £2.5 million per annum)

¹⁵⁹ Department of Health. *Transforming Community Services and World Class Commissioning: Resource Pack for Commissioners of Community Services*. London: Department of Health, 2009 (January).

Street sex working now contained within this borough within Northamptonshire

In addition, SWAN's 'Operation Uncanny' provides an innovative measure to tackle sex working in residential areas¹⁶⁰: a 'toleration area' where sex workers were not arrested for soliciting.

The SWAN partnership has been cited as an example of good practice in improving life chances for sex workers on a number of occasions. In addition to citation in the world class commissioning resources¹⁶¹, it was the top-ranking intervention in the Home Office supported 2010 Tilly Awards for reducing crime (out of 110 entries) on the grounds of its 'robust analysis, comprehensive response, and the number of partners actively engaged in Operation Uncanny's delivery'. Police monitored the area to identify and arrest customers. The programme was also cited on the Local Government Improvement and Development website¹⁶². **Grade G3 [NIE]**

Local authority-wide multi-agency partnerships that address health inequalities, enforcement issues, and exiting sex work

This is now emerging as the preferred service model amongst local authorities for delivering health and harm reduction services to sex workers. Such partnerships frequently also accord importance to the anti-social behaviour caused by street sex work, developing routes out of sex work and enforcement action against brothel keepers and kerb crawlers. Though costly (up to £2 million per year¹⁶³), they are underpinned by a strong political commitment and by explicit shared beliefs regarding sex work which is not seen as a choice nor an occupation. These services are different from, say, Open Doors which is a non-judgemental specialist NHS service run from a health perspective and not by a formal partnership board. There are a number of examples of these services that are cited as good practice.

<u>London Borough of Newham</u>: Newham's multiagency service is still in the planning stage but the borough is seen as a good practice example in how it has used local and national intelligence in scoping this provision. It has undertaken this as an Inclusion Health 'Scrutiny Development Area' project¹⁶⁴. The aim is to develop a holistic and joined-up approach to sex working by bringing

¹⁶⁰ Home Office Press Notice. 'News Story: Tilly Awards recognises crime-cracking initiatives'. 8th November 2010.

¹⁶¹ http://www.commissioningsupport.org.uk/idoc1136.pdf?docid=7252b444-a75a-4234-8956-b2ab068c07c6&version=-1

¹⁶² http://sitetest.idea.gov.uk/idk/core/page.do?pageId=1

¹⁶³ This was the cost of carrying out the whole of Lambeth's Violence Against Women and Girls Strategy: in terms of the sex work strand this has a budget of around £600,000 per annum.

¹⁶⁴ Draft Report of the Crime and Disorder Scrutiny Commission into Street Prostitution in Newham. December 2012.

together and involving the full spectrum of partners who work with sex workers in Newham, establishing a shared position recorded in a joint statement, providing mechanisms for monitoring the level of sex work, providing exit routes for women involved in sex work, using enforcement action to target those buying sex, informing and involving the community, and ensuring a value for money approach (through piloting the Centre for Public Scrutiny's return on investment (ROI) model). It anticipates a 50% reduction in sex working in the borough within a few years and a reduction in health inequalities in this group that needs to be investigated through the JSNA process. Thus, this approach has a wide remit, including addressing anti-social behaviour, tackling the health issues affecting sex workers (such as drug abuse, increased risk of sexually transmitted infections, and threats and acts of violence they receive), and helping women out of sex work.

The evidence gathering has involved monthly evidence-gathering meetings, in-depth discussions amongst stakeholders, interviews with experts from different organisations, observing police and council enforcement operations, attendance at open meetings organised by outside bodies, a survey of service providers, a small survey of street sex workers, and desktop research (including the mapping of all incidents relating to street sex work over a 10-month period and estimation of the numbers of street sex workers and their clients using data from the police and drug/alcohol agencies). **Grade [G2, NIE]**

<u>Suffolk</u>: The Suffolk Prostitution and Sexual Exploitation Strategy was set up following the murder of 5 sex workers in Ipswich in 2006, which aimed to treat the sex workers as 'victims' and to instigate a zero tolerance policy towards kerb crawlers. A multi-agency team was developed, comprising 3 dedicated police officers, a manager from social care, a practitioner from child protection, an adult support worker, and a housing support worker. An emphasis is placed on developing routes out of sex work, taking enforcement action, and stopping coercion into sex work taking place. According to Suffolk County Council there has been no street sex working and no kerb crawling in Ipswich since 2008. The good practice in this intervention appears to be the elimination of sex working and its clientele from Ipswich. **Grade [G4]**

Lambeth: In 2011 the London Borough of Lambeth has developed a Violence Against Women and Girls Strategy which is owned by the Safer Lambeth Partnership. The strategy covers 8 strands: domestic violence, sexual violence, stalking, trafficking for sexual exploitation, 'prostitution', female genital mutilation, forced marriage, and honour-based violence, thereby folding sex work into a bundle of dangerous and criminalised activities. The partnership sees the women as 'victims' and the men as the perpetrators of abuse. The partnership addresses demand through action against kerb crawlers; supports women to exit sex work (providing drug testing and treatment, working with St Mungo's to provide an accommodation pathway, proving support to victims of gender violence (seeing over 1000 women and 40 men in the year 2012), and a multi-agency risk assessment

conference for the most vulnerable women); undertakes prevention work (school education and awareness work and work in targeted services); and involvement of the community (work with community groups, the reporting of incidents). **Grade [G4]**

Components of good practice

Use of mobile vehicles in outreach work:

Though few examples have been found of the use of mobile vans to deliver an outreach service¹⁶⁵, there is evidence that they can provide an effective outreach service. One25's van now (2013) goes out in Bristol 5 nights per week and provides nutritious food, hot drinks, and an opportunity to talk and get advice in a safe space¹⁶⁶. The organisation provides access to a mobile phone to contact emergency hostels, information on 'ugly mugs' (perpetrators of street violence), warm clothes, personal alarms, first aid, and condoms. Once a week experienced staff and volunteers go out on foot to speak individually with the women, especially younger sex workers. One25 also works to support exit from sex work. Similarly, MASH (Manchester Action on Street Health), founded in 1991, provides a dedicated nightime street outreach service two nights a week at locations across Greater Manchester using a van¹⁶⁷. The outreach service offers free condoms and lubricants, sexual health advice, needle exchange, harm reduction and advice/information, a dodgy punter reporting service, personal attack alarms, assessments/care planning, referrals intro drug and other services, and refreshments. The SAFE Project aims to promote the health and well-being of female sex workers aged 18 or over in Birmingham, Sandwell and Walsall. As part of the evening outreach project, once a week the SAFE van visits areas of the city where sex workers work outdoors¹⁶⁸. The van is staffed by two health workers who distribute condoms and lube, and also offer a needle exchange service. They are also available to give advice on a variety of social issues that may concern sex workers. The UKNSWP identifies use of an identifiable vehicle in outreach work (for example, as a place to carry out risk assessments) in its good practice guidance¹⁶⁹ and there is some evidence that street sex workers particularly value some of the services a vehicle can supply in meeting basic needs (like a space to talk, shelter, obtain food, etc.). Grade [G4]

¹⁶⁵ The two examples identified are the Fleur de Pavé organisation (funded by a public-private partnership) in Lausanne, Switzerland, that operates a mobile van parked in Lausanne's sex work zone five night a week. It provides condoms, needle exchange, psychological support, and shelter in cold weather (see Darling, Gloor *et al.*, 2012); Jeal & Salisbury (2004) mention the work of One25, a charity in Bristol that supports sex workers by operating an outreach van until midnight and a drop-in service during afternoons. A mobile van is used in some US sex worker interventions, see:

http://www.salamandertrust.net/resources/15JbgDec12SexWorkerDemographicsGBV.pptx.pdf

¹⁶⁶ http://www.one25.org.uk/what_we_do/index.php

¹⁶⁷ http://www.mash.org.uk/default.asp?pid=52

¹⁶⁸ http://www.safe.wmids.nhs.uk/how.asp

¹⁶⁹ http://www.uknswp.org/wp-content/uploads/GPG2.pdf

Use of cultural mediators and peer educators:

While extensive use has been made of cultural mediators and peer educators in outreach work in low and middle income countries and mainland European countries, such use has been much more limited in Britain. The use of cultural mediators may be an effective intervention with migrant off-street sex workers. When SHOC employed two bilingual workers to work with this group, there was a significant increase in the use of its sexual health clinics by these workers. The role also proved effective in building trust and engagement. The evaluators of this service thought the targeted provision for migrants could be further enhanced in the future by training bi-lingual workers to be cultural mediators¹⁷⁰. According to TAMPEP's (European Network for HIV/STI Prevention and Health Promotion Amongst Migrant Sex Workers) definition, 'cultural mediators are a go-between who know the motivations, the customs and the codes of dominant culture in the host country, as well as the conditions, social ethics and the scene in which a minority group finds itself. They should be individuals capable of eliciting trust from the target group, and should be of the same ethnic group and nationality as the sex workers. Cultural mediators are intercultural bridges contributing to the decoding of cultural codes in order to facilitate understanding of health and social issues'¹⁷¹. **Grade [G4]**

In contrast to cultural mediators, '...peer educators are members of the migrant sex worker community, and therefore identify completely with the target group. They play the role of leaders and articulate the interests of their peers. Their involvement provides not only interpretation and an intercultural bridge but provides a role model for other migrant sex workers, increasing self-esteem and self-confidence amongst migrant sex workers. There are some preconditions for effective peer education: peer educators must have a base in the community and must be recognised as leaders, while at the same time representing the project'. No examples have been found in Britain of peer educators in this role. Some sex work projects use former sex workers as volunteers, for example, MASH relies heavily on a large pool of around 40 volunteer staff recruited from a range of backgrounds, including workers from the drug and sexual health field, nurses, students, former sex workers and drug users to provide its various outreach services.

However, cultural mediators and peer educators are much more embedded into practice in some European countries. TAMPEP provides a *European Manual of Good Practices in Work with and for Sex Workers* that provides a number of examples of good practice in the use of both cultural mediators

 ¹⁷⁰ See: Institute for the Study of European Transformation. *Evaluation of the Services Offered to Migrants in Haringey and Enfield by SHOC. Final Report.* London: London Metropolitan University, 2011 (February).
 ¹⁷¹ See TAMPEP International Foundation. *Cultural Mediators in the Area of Prostitution/Transnational*

Training. Manual. December 1998 & April 2001.

and peer educators¹⁷². With respect to <u>cultural mediators</u>, the manual provides the example of workshops with nurses for <u>female and transgender migrant sex workers in Hamburg</u>, <u>Germany</u>, which has been carried out by Amnesty for Women since 1995. Regular outreach work is carried out with cultural mediators and migrant nurses to make contact with female and transgender migrant sex workers in private apartments and brothels. The aim is to spread information on legal rights and health issues, to deliver workshops on safer sex and HIV/STI prevention, to empower, and to refer to other support organisations in the city. The following steps are pursued: mapping the city and creating an address list; formation and training of the international team according to the local situation; compiling the materials needed; planning a work schedule; conducting the outreach activity; documenting each instance of outreach; and monthly exchanges and evaluation meetings with the team.

The cultural mediator chooses the day route, checks the address, and prepares the materials (including 'grab bags' containing condoms, lubricants, syringes, contraceptives, tampons, and sponges). Each outreach activity takes about 5 hours and is undertaken in the afternoon. A visit is always conducted by two people: two cultural mediators or one cultural mediator and one (migrant) nurse. The workshops are given spontaneously, according to sex workers' questions. The nurse and cultural mediator answer questions, show pictures, demonstrate how to do a breast exam, and make referrals to the public health service or other organisations. The duration depends on sex workers' availability and may be from 10 to 60 minutes. Sex workers inform staff of other addresses where they can find sex workers and sometimes refer their colleagues to Amnesty for Women.

A sheet is completed with information about each apartment or brothel visited. In addition, after each outreach activity, the cultural mediator and nurse are responsible for writing a short report. Evaluation is undertaken informally by sex workers during and after the workshops. An official evaluation is carried out by the outreach coordinator and the team in annual final reports. These show that the presence of cultural mediators and (migrant) nurses increases reliability, the workshops increase the sex workers' knowledge (and is very effective at identifying gaps) and improves their negotiating skills, and the knowledge gained empowers the sex workers. Outreach work is fundamental because of the migrant sex workers' isolated working conditions and has to be done regularly because of the mobility of migrant sex workers. **Grade [G4]**

<u>Outreach with peer educators</u> is exemplified by <u>Autres Regards' work with female street-based sex</u> <u>workers in Marseilles, France.</u> Outreach is carried out by peer educators (sex workers), on foot and with a mobile unit, both day and night, to inform about HIV/STIs and violence prevention and legal rights and to distribute condoms and lubricants. The aim is to empower sex workers by highlighting

¹⁷² TAMPEP. Work Safe in Sex Work. European Manual of Good Practices in Work with and for Sex Workers. Amsterdam: TAMPEP International Foundation, 2009. Accessed at: http://tampep.eu/documents/wssw_2009_final.pdf

their role in delivering safer sex and HIV/STI prevention messages and to defend their rights as sex workers, women, and migrants. The following steps are undertaken: increasing outreach activities because only some of the sex workers were taking up the services offered by the counselling centre; preparation of the materials for outreach (information, condoms, and lubricants); checking the last outreach report for information on where new sex workers have been seen and when; touring Marseilles on foot or with the mobile unit; and return to office and report compilation.

The association of Autres Regards was created by sex workers and they have been part of the team since its start in 1995. Despite the subsequent employment of more social workers, Autres Regards has kept peer educators on the team because of their important role in prevention work and expertise in speaking about sex work. Outreach is carried out every working day (three times during the day and twice at night) at locations in and around Marseilles. Sex workers comprise part of the outreach teams and write the report after each outreach session. Sex workers contacted during outreach provide feedback. The team consists of social workers, a nurse, cultural mediators, and peer educators. Outreach is always conducted by two people: nurse and peer, cultural mediator and peer, doctor and social worker, or social worker and peer. Materials brought along on every outreach session include condoms, lubricants, harm reduction materials, and information leaflets. The mobile outreach unit also provides for hot drinks, fruit and cakes.

Evaluation is conducted by the outreach team, the peer educators, and the target group during outreach. This model facilitates contact with sex workers who do not come to Autres Regards' office and react positively to the presence of peer educators during outreach work (permitting more open discussions about their work and its dangers). Amongst lessons learned was the need for better cooperation between peers and social workers regarding the rules/codes of outreach work, to avoid peers having to be solely responsible for the work. Spontaneous unplanned discussions sometimes happen at the office that pull in sex workers but these need resourcing by team members including peers. Grade [G4]

The facilitation of implementing sexual health testing in good outreach settings

There is evidence that good practice in outreach facilitates testing commercial sex workers for chlamydia and gonorrhoea in this setting. For example, to assess the feasibility of testing indoor commercial sex workers for *Chlamydia trachomatis* and *Neisseria gonorrhoeae* in an outreach setting (sometimes termed 'in-reach'), all commercial sex workers seen on outreach over a 6-week period were offered self-taken vulval swabs for chlamydia and gonorrhoea testing. Feasibility was assessed by all the outreach workers on a standardised proforma. Of the 93 women offered the service, 40 accepted, of whom five (12%) had not previously accessed sexual health services. The majority of

women declining the service had recently attended a sexual health clinic. Three cases of chlamydia and one of gonorrhoea were diagnosed. The cost per sexually transmitted infection was £392.50. Most of these women were knowledgeable about sexual health and were already having regular check-ups, but a significant minority did not know how to access STI care. The investigators (a collaboration between Open Doors, City and Hackney PCT, London, and the Department of Sexual Health, Homerton Hospital, London) concluded that offering STI testing on outreach was feasible and cost effective¹⁷³. **Grade [G2, IE]**

Summary: Elements of good practice in service models

One of the factors that appears to determine the success of sex worker interventions is size or critical mass of users. The evidence base provides several examples of small projects run by voluntary organisations whose services in a particular local authority were terminated when funding ran out, or local authorities were confronted with budget constraints, or the intended outcomes were not attained. A typical picture at local authority level is provided for Newham: '...different organisations doing bits of work here and there around these issues started to emerge'. The Women and Girls Network (WGN), a pan London organisation that provides counselling, support, and hostels for women who have experienced gender-based violence, tried to map the organisations in Newham working with street sex workers. The WGN noted: '...there seemed to be no joined up working between the organisations. At the same time, organisations were not sharing information with each other and competing to get access to limited funds. This all meant that in reality the women were being told different things by different services and were getting a disjointed service that did not address the issues they faced'.

This clearly presents a dilemma for charity sector or faith-based organisations whose funding is limited and the viability of their services brought into question, resulting in a lack of continuity of care for sex workers. Many of these services did not monitor the number of sex workers using them and consequently how much the service spent on these clients. The most problematic gap was that many were not able to offer case management or care pathways to help these women¹⁷⁴. When Newham Council undertook its own mapping of services, it found that: 'It is only the organisations that are aimed specifically at the women, such as the Sex Worker Clinic at Greenway Sexual Health Centre, Open Doors, and WOTS, which have more than eight pathways for further referral for the

¹⁷³ S Macauley, S. Creighton. Testing commercial sex workers for chlamydia and gonorrhoea on outreach. *Sex Transm Infect* 2009;85:231-232 doi:10.1136/sti.2008.034199.

¹⁷⁴ Draft Report of the Crime and Disorder Scrutiny Commission into Street Prostitution in Newham. December 2012.

women. This might suggest that these services are the best set up to address the needs of the women as they give the women access to additional services to address their different needs'.

The following elements of good practice were identified:

- 1. For statutory service models, there is agreement that sustainable multi-agency integrated approaches work best rather than silo or single-agency approaches. This is because of the complex needs of sex workers and the nature of the policy environment. If the service is to be holistic, then a wide range of services, knowledge and skills need to be accessed. With respect to the multi-agency service models developed, many local Councils attempt to balance the health inequalities of sex workers with a focus on the safety concerns and quality of life of the community where sex work takes place, so multi-agency partnership working may also encompass exit strategies. A good example of this approach is the SWAN partnership.
- 2. Key elements of effective service have been identified by the UK Network of Sex Work Projects (these arose from a survey of members of UKNSWP¹⁷⁵):
 - Services responsive to the expressed needs of sex workers and reflecting diversity among service users (including acknowledging that not everyone wants to leave the sex industry)
 - Rapid access to services for indoor and outdoor workers who need them
 - Multi-agency and joined-up working
 - Flexibility and holistic provision (including possibly one-stop shop)
 - Open access to services
 - Non-judgemental approach
 - Specialist staff providing support and advocacy as well as advice and practical provision
 - Different facilities including outreach and drop-in.

Other issues that would help projects provide more effective services to sex workers were identified as:

- Sufficient and sustained funding
- Involvement of specialist projects in multi-agency forums
- Education for agencies in the criminal justice system to tackle stigma
- Access to supported housing / safe refuges for sex workers with complex needs
- Anonymous service delivery to the indoor and outdoor sectors

¹⁷⁵ Pitcher J, Laing M. *UKNSWP member survey on laws and service provision. Report on findings.* UKNSWP, June 2012. Accessed at: http://www.uknswp.org/wp-content/uploads/Results-UKNSWP-member-survey-laws-services-fin.pdf

- 3. With respect to UKNSWP's requirement for services to be responsive to sex workers' expressed needs, a sample of female street sex workers indicated the following if designing a service for women sex workers¹⁷⁶:
 - Nearly all (97%) wanted a doctor who could provide an integrated service for primary care, reproductive health, and substance abuse
 - 89% wanted condom provision
 - Around three-quarters (75-77%) wanted a location near their place of work, basic needs of cleanliness and sustenance met (showers, food and drinks), needle exchange, and evening/night opening
 - Around half wanted counselling (56%) and a facility to wash clothes (46%).
- 4. From the studies described in this report and the wider literature, a number of components of good practice can be identified (some of which accord with those elements identified by the UKNSWP and street sex workers):
 - Adequate funding emerges as a key issue to sustain services and provide continuity for clients. Amongst 'lessons learned', the SWAN partnership included the need 'to ensure that funding for posts are mainstreamed'. Indeed, the Newham scrutiny report cites two examples where agencies working with sex workers that were not mainstreamed had either had to scale down their services or close altogether for reasons of funding shortfalls.
 - A minimum critical scale of working is needed for an organisation or agency to be able to embark on case management and to establish or utilise appropriate care and referral pathways. Also assured continuity of a service is needed by sex workers.
 - As with other vulnerable groups, there is an identified need for services to remain close to their sex worker clients, hence the argument that sex work projects should be part of sustainable multi-agency partnership working, as they have built a trust with their sex worker clients (many studies emphasise the importance of these bonds of trust which may be particularly important in working with migrant, off-street sex workers who may fear deportation). Open Doors works closely with services building a relationship with them.
 - Addressing stigma appears to increase the effectiveness of services. This may
 encompass offering gender specific spaces and gender appropriate clinical staff and
 specialist services for 'trans' sex workers. Studies report low rates of disclosure in all
 health care settings. This could be addressed by training and access to relevant

¹⁷⁶ Jeal & Salisbury (2004), *ibid*.

guidelines¹⁷⁷ or by developing partnerships between general practice and specialist STI clinics (where sex workers appear to be more at ease with regard to disclosure)¹⁷⁸. SCOT-PEP in Edinburgh has recommended that an exploration take place with the Department of Genito-Urinary Medicine to develop training for GPs in Edinburgh and to offer a fast track referral facility for women working in the sex industry¹⁷⁹. Open Doors, the multidisciplinary statutory service, provide sex workers with case management and advocacy, actually going with women to services and specialist help rather than just sign-posting the women. Similarly, WOS (Women's Open Space Project), operating in North London, provide advocates to help street sex workers register with a GP¹⁸⁰.

Given the chaotic lifestyles of street sex workers, the use of outreach workers, drop-in centres, and no-appointment arrangements may increase engagement with heathcare service providers (with outreach during nocturnal hours and premise-based services provided outside the hours of 9 to 5¹⁸¹). Appointment systems may be particularly problematic, the NHS London Sexual Health Programme noting that street sex workers '...often lack basics like a contact telephone number. They may be living in a hostel, not have a permanent contact address or not be residents of the borough'. Street sex workers are frequently homeless, access to supported housing (or the inclusion of a housing support worker who can bring in housing services) being needed for sex workers with complex needs.

Implications for further research/evaluation

1. There is an emerging consensus that health interventions are best delivered within a service model of holistic, joined-up multi-agency partnership working. However, amongst authorities undertaking scrutiny work, it is clear that two different options are available: (i) Multiagency partnerships led by a partnership board and underpinned by an agreed position or joint statement, embedded within crime and disorder scrutiny and strategy processes and in which community safety, anti-social behaviour, and exit work figure prominently. These models are underpinned by a value system which endorses the view that sex work is not an occupation and utilises the term 'prostitute'. (ii) Multi-agency working led by the NHS and without

¹⁷⁷ Jeal and Salisbury (2004), Implications, 518.

¹⁷⁸ Nguyen, Venne, et al. (2008), Discussion, 177-80.

¹⁷⁹ Sexton S. A Stitch in Time. A short study into the needs of women working in the sex industry in Edinburgh. Edinburgh: SCOT-PEP, 2003 (April).

¹⁸⁰ Sanders-McDonagh E, Neville L. *Women's Open Space Project Evaluation: Final Report*. London: Middlesex University London, 2012 (September).

¹⁸¹ Safe Exit. A Template for a Multi-Agency Approach to Tackling Street-Based Prostitution.

formal partnership boards where a health perspective is taken: the value system is nonjudgemental and the term used is 'sex worker'. Since, for optimal outcomes, multiagency working needs to encompass voluntary sector sex work projects, research is needed to investigate which of these service models yields the best outcomes for sex workers.

- 2. Currently, low levels of collection of 'sex worker' status in data systems amongst partners in multi-agency partnerships is inhibiting the planning of services. Key data may be unavailable, of poor quality (through non-disclosure/underreporting, for example), or conflicting. The mapping and profiling of street sex working frequently has to rely on a multiplicity of sources to provide estimates, such as data from police monitoring, custody data, data from drug, health, and sex worker projects, etc. There is little data on off-street prostitution, a group which usually outnumbers street sex workers many fold, which may result in a focus on sex street workers. Attempts to use return on investment scrutiny models in planning services have been limited by the lack of recording of 'sex worker' amongst users of services and, consequently, the inability to estimate service costs. Research is needed on the feasibility of mainstreaming 'sex worker' data collection and reporting using standard templates across partners in multi-agency partnerships.
- 3. In many UK cities and towns off-street sex workers significantly outnumber on street sex workers. They are substantially more hidden, more mobile, and a high proportion are migrants. For example, amongst off street sex workers that Open Doors works with in the London Borough of Newham, 42% were Eastern European (mainly Romanian), 37% Brazilian, 8% White British, and 12% other ethnicities¹⁸². The challenges of outreach work are different: off-street sex workers frequently have a poorer knowledge of services, limited or no skills in the use of English, sometimes complex relationships with 'pimps' that do not conform to stereotypes, and a fear of institutions such as the police and an antipathy to engagement with such institutions and some statutory services (often linked to their irregular migrant status, including 'irregular' paperwork). Though there are pockets of good practice (such as Open Doors and SHOC), there has been only limited exploration of innovative models of outreach engagement compared with practice in mainland European countries. The use of bilingual workers trained as cultural mediators¹⁸³ and of peer educators have been
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http://mgov.newham.gov.uk/documents/s79058/Review%20into%20sex%20workers%20DRAFT%20v%205.pd f (para. 2.34).

¹⁸³ Staff with the appropriate language skills and with an understanding of migrants' culture.

suggested as good practice¹⁸⁴. TAMPEP (European Network for HIV//STI Prevention and Health Promotion amongst Migrant Sex Workers) has done much to promote such models. In addition, the use of the internet, or 'netreach' is a new form of outreach where projects make contact with sex workers using the internet. Research is needed to examine the utility of these models and their transferability to the UK context, especially outreach work with indoor sex workers. This is now a priority as the number of migrant sex workers, especially from Eastern European countries, has increased markedly over the last two decades.

4. Significant levels of non-registration with GPs and low levels of disclosure of 'sex worker' status results in suboptimal care and the loss of opportunities for preventive care, including referrals for screening. The interventions reviewed yield a number of remedies, including training, use of guidelines, a role for advocates, and partnerships between GUM/sexual health or obstetrics/gynaecology clinics (where disclosure rates are higher) and GPs to embed good practice. Research is needed to test the efficacy of these approaches to increase GP registration and the disclosure of 'sex worker' status in this setting.

¹⁸⁴ Institute for the Study of European Transformation. *Evaluation of the Services Offered to Migrants in Haringey and Enfield by SHOC. Final Report.* London: Middlesex University, 2011 (February).

Appendix 1: A note on terminology and conceptualisations.

Asylum seekers and refugees

Included in the definition of vulnerable migrants are asylum seekers (including failed asylum seekers), refugees, and undocumented or irregular migrants (including those who have entered the country illegally and migrants with irregular documentation, such as visa overstayers). Other groups may be vulnerable with respect to health care access (e.g. students from overseas).

Gypsies and Travellers

The term frequently used in this report is 'Gypsy or Irish Traveller', the category label in the 2011 England and Wales Census. The term 'Gypsy / Traveller' is also used. Both terms are used in this report to also encompass Roma. The Annual School Census in England makes this explicit through the use of the terms 'Gypsy/Roma' and 'Traveller of Irish Heritage'. Some have used the contraction 'GRT' for this population. Whichever label is used, the terms are always capitalised.

However, much of this terminology continues to be contested. The term 'Gypsy / Traveller' or 'Gypsy or Irish Traveller' does not necessarily include Roma in terms of policy definitions (the 2011 Census term was intended to exclude Roma). The Department for Education category 'Gypsy/Roma' is currently being questioned by the Department for Education Gypsy, Roma, and Traveller stakeholder group as it conflates Roma with English Romany Gypsies¹⁸⁵. The Ministerial Working Group report has been criticised for its focus on ethnic Gypsies and Travellers to the exclusion of Roma (except for the chapter on education), although the Roma as a separate group is acknowledged (para. 1.6). For recent migrant Roma, poor English may be a barrier to accessing primary care services.

Homeless persons:

The preferred generic term is 'people who are homeless' though, for reasons of economy, this term is sometimes contracted in this report. The segment of this population who are vulnerable is defined by the Department of Health as people who are rough sleepers or those sleeping in a hostel, a squat or on friends' floors (insecure or short-term accommodation). These groups frequently cycle in and out of street homelessness. The definition does not include people such as families (with children) living in temporary accommodation provided by a local authority under homelessness legislation. The definition also excludes people living in overcrowded or unsuitable accommodation. However, it is

¹⁸⁵ Personal communication, Matthew Brindley, ITMB.

acknowledged that persons who fall into these other categories of homelessness may also experience vulnerability. They are excluded because '... although their housing may be unsettled (potentially leading to increased health problems as a consequence), they are not considered to have substantially different health needs to the mainstream population, and will not generally have significant problems in accessing primary health care'.

Sex workers:

Throughout this report the term 'sex worker' has been used in contradistinction to 'prostitute' which has derogatory connotations. The choice of terms in the policy literature varies. While bodies such as the Department of Health and National Inclusion Health Board use 'sex worker', the salient term in Home Office publications is 'prostitute'. Sometimes, the use of 'prostitute' is deliberate to emphasis the 'anti-social' nature of sex working. For example, Newham's Crime and Disorder Scrutiny Commission so justify the use of the term 'prostitute'¹⁸⁶: 'Throughout this report the Commission has used the term prostitution, prostitute and women involved in prostitution. The Commission recognises that for some people that using these terms will be seen as giving a certain message about the Commission's views of the people involved in these activities. However the Commission wants to note that it does not use the terms to make a political, moral or judgemental view on prostitution or to emphasise if the people involved have chosen or not chosen this path. Instead the commission wants to make clear that with this review it has not been concerned with making a statement on those involved or the work, instead it was interested in how the Council and its partners responded to the many issues caused by these activities and faced by those involved in them. Indeed, during the reviews the Commission had been using the term sex worker, however at the end of the review it felt that the term sex workers sanitised the subject and wanted to make clear that this was an issue that had to be dealt with. Therefore, it opted to use the more striking term of prostitution'. Lambeth and Suffolk Councils also use 'prostitute', in contradistinction to Open Doors, an NHS-led specialist service that prefers 'sex worker'.

People involved in sex work themselves favour the term 'sex worker', as do projects concerned with sex work and the umbrella organisation for such projects. There are benefits in using the term that is salient amongst people involved in sex work as it avoids giving offence and invoking judgemental attitudes. This debate is redolent of that relating to 'gay' persons (the term of choice of those who hold the identity), as opposed to that of the medicalised and legalised term 'homosexual'.

Sex workers are not a homogeneous group. Sex work projects emphasise the importance of gender identity. Sex workers may conduct their work on or off street, the two sectors having quite distinctive profiles and patterns of health risk. Off-street sex workers are mainly migrants. Sex workers may be

¹⁸⁶ Draft Report of the Crime and Disorder Scrutiny Commission into Street Prostitution in Newham. December 2012.

'trans' (trangendered/transsexual), some of whom may also describe themselves as 'transvestite'. The majority of 'trans' sex workers are male to female and may be pre-op or post-op and a significant proportion are migrants. Girls and women who are victims of trafficking may have been forced into sex work and, consequently, find terms such as 'working girls' or 'sex workers' unacceptable.

There has been much debate in the scholarly literature and the media about the exercise of agency in the undertaking of off street and street-based sex work. Some jurisdictions portray sex workers as *victims*, such as Newham¹⁸⁷, Lambeth¹⁸⁸, and Suffolk Councils¹⁸⁹, sometimes for understandable reasons¹⁹⁰, though recently Merseyside Police decided to amend the use of the term 'victim-based approach' in its Sex Worker Strategy to 'holistic approach'¹⁹¹. Pai (2013)¹⁹² depicts Britain's migrant sex workers as vulnerable, coerced victims who make 'choiceless choices'. While this description would accurately describe trafficked migrant sex workers, constructing all women in sex work as passive victims and the objects of pity strips them of the agency they may exercise in shaping their lives and projects.

Those who work in the sex industry encompass some who are there through choice and others who are forced or coerced into this work. Some 'post-feminists' have, controversially (given, not least, the striking burden of health inequalities, including significant risk of violence, and the implicit disregard for issues of community safety and quality of life), emphasised the empowering nature of sex work, such as Brooke Magnanti in *Belle de Jour* (her blog of life as a sex worker¹⁹³). Catherine Hakim's recent book *Honey Money*¹⁹⁴ celebrates those women who financially benefit and gain independence by sex work. Even some women in Pai's study chose to enter sex work to earn significant sums of money (amounting to £400 to £800 a day) to buy property in their countries of origin, pay off debts, or to make remittances to family members. The NHS London Sexual Health Programme has also indicated that many 'trans' sex workers are migrants who are selling sex to pay for gender reassignment surgery, for example, SWISH (covering the Royal Borough of Kensington & Chelsea, London Borough of Camden, and City of Westminster) reported that of their 'trans' service users seen 1 April to 30 September 2010, 36% stated that they were selling sex to pay for GRS, while almost half of the migrants were on student visas.

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http://mgov.newham.gov.uk/documents/s79058/Review%20into%20sex%20workers%20DRAFT%20v%205.pd f.

¹⁸⁸ Safer Lambeth Partnership. Safer Lambeth's Violence against Women and Girls Strategy, 2011-14. 2011.

¹⁸⁹ Suffolk County Council. Suffolk Prostitution and Sexual Exploitation Strategy. 2011.

¹⁹⁰ Suffolk's policy was developed following the murder of five sex workers in Ipswich, Suffolk, in 2006.

¹⁹¹ http://www.merseyside.police.uk/media/76404/cog_minutes_december_2012.pdf

¹⁹² Pai, Hsiao-Hung. Invisible: Britain's Migrant Sex Workers. London: Westbourne Press, 2013.

¹⁹³ <u>http://belledejour-uk.blogspot.co.uk/</u> and Maganti B. *The Intimate Adventures of a London Call Girl*. London: The Orion Publishing Group, 2005. She is now a research scientist.

¹⁹⁴ Catherine Hakim. *Honey Money. Why attractiveness is the key to success.* London: The Penguin Press, 2012 (August).

Clearly, considerations of agency can be eschewed in providing health-related services in a nonjudgemental manner. However, they may be germane when deciding on the extent to which multiagency holistic sex worker interventions should encompass and integrate measures addressing health inequalities with those concerned with the delivery of law enforcement outcomes and pro-active exit work, as a growing number of local Councils now favour. Some sex workers have indicated in surveys that they do not wish to exit, while others who have increased their work options through education and qualifications have elected to stay in sex work. The extent to which multi-agency interventions can always be underpinned by a shared position for all partners, including participating specialist sex work projects, may depend on how such views are allocated across participants.

Appendix 2: Membership of the Data and Research Working Group of the National Inclusion Health Board

Dr Peter J Aspinall, Reader in Population Health, University of Kent

Mr Matthew Brindley, Policy and Research Officer, Irish Traveller Movement in Britain

Dr Paramjit Gill, Reader in Primary Care Research, University of Birmingham

Prof Peter Goldblatt, Deputy Director of the Institute of Health Equity, UCL, London

Dr Andrew Hayward, Reader in Infectious Disease Epidemiology, UCL, London

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Ms Helen Mathie, Policy Manager, Homeless Link

Prof Joanne Neale, Prof of Public Health at Oxford Brookes University (to March 2013)

Prof Jennie Popay, Prof of Sociology & Public Health in the School of Health & Medicine, Lancaster University (to April 2013)

Mr Martin Gibbs, Health Inequalities Unit, Department of Health

Miss Alison Powell, Health Inequalities Unit, Department of Health (to April 2013)