



**Evidence pack**  
March 2010

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# Executive summary

The last few years have seen modernisation and reform in health services lead to a transformation in the accessibility and quality of care: investment in the NHS is at record levels; waiting times are shorter than they have ever been; more people than ever report satisfaction with the NHS; more people than ever before are registered with a GP. This has led to a transformation in health outcomes: life expectancy is at a historic high and infant mortality at a historic low.

While significant progress has been made in delivering improvements in health outcomes across the population, meeting the needs of those with the most complex health needs remains a considerable challenge.

This evidence pack is the product of extensive consultation and research (see annex D). It brings together existing and new analysis on the primary health care needs of the socially excluded, highlights the case for change and underpins the resulting Inclusion Health agenda and publication, *Inclusion Health: Improving the way we meet the primary care needs of the socially excluded* ([www.cabinetoffice.gov.uk/social\\_exclusion\\_task\\_force/short\\_studies/health-care.aspx](http://www.cabinetoffice.gov.uk/social_exclusion_task_force/short_studies/health-care.aspx)).

The research confirms that a small but significant group of the nation's most vulnerable people continue to suffer from poor health outcomes across a range of indicators including self-reported health, life expectancy and morbidity. The analysis highlights that health inequalities persist, and that socially excluded groups experience a range of health needs, which can be exacerbated by social factors. Furthermore, socially excluded people often make chaotic and disproportionate use of health care services, and experience a range of barriers and issues relating to their access and quality of primary care. The costs of failure are great not only to the individual life chances of socially excluded clients, but also to the taxpayer, services and the communities who pick up the pieces. Through analysis of the system and services (specifically through the lens of four groups and two geographical areas), the research draws out a range of challenges that remain in meeting the primary health care needs of socially excluded groups, and identifies areas of promising practice.

We are grateful to everyone who has contributed to this report, and hope it will prove a useful resource in improving the health outcomes of some of the most vulnerable members of our society.

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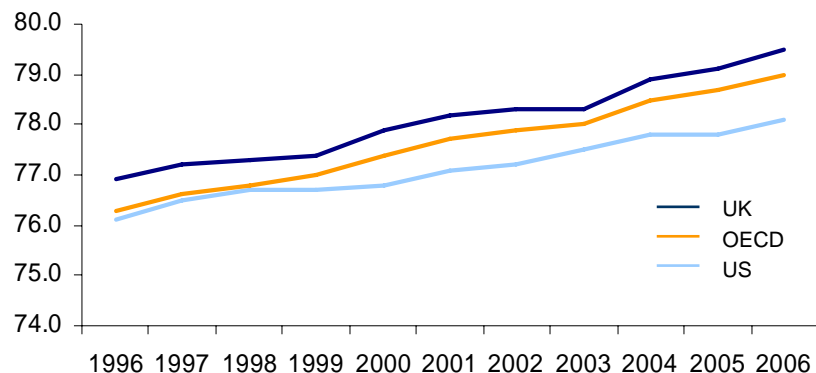
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# Over the last decade, significant progress has been made to improve the health outcomes of the population as a whole

## A range of indicators point to improving health for the UK population as a whole...

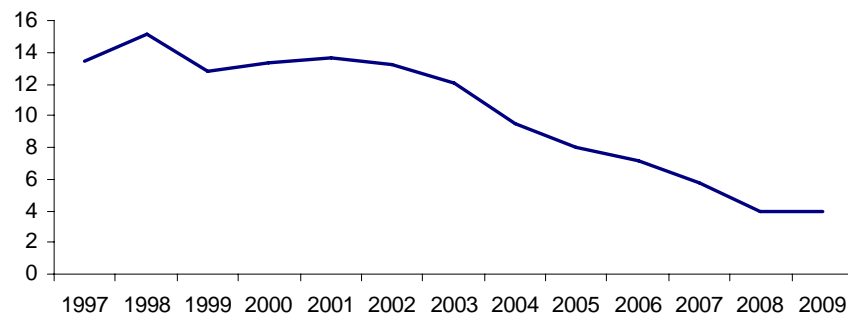
Life expectancy<sup>1</sup>



- Average life expectancy for all groups in England has increased significantly – for males by an extra 3.1 years and for females by an extra 2.1 years between 1995-97 and 2005-07<sup>2</sup>
- Infant mortality rates have fallen to an historic low over the last 10 years, having decreased from 5.6 infant deaths per 1,000 live births in 1995-97 to 4.7 per 1,000 in 2005-07<sup>3</sup>
- Fewer people now die from heart disease and cancer, with mortality rates among under-75s decreasing by 47% and 19% respectively, since 1995-97<sup>4</sup>

## ...this has been matched by improvements in the quality of the healthcare system

Average inpatient waiting time (weeks)<sup>5</sup>

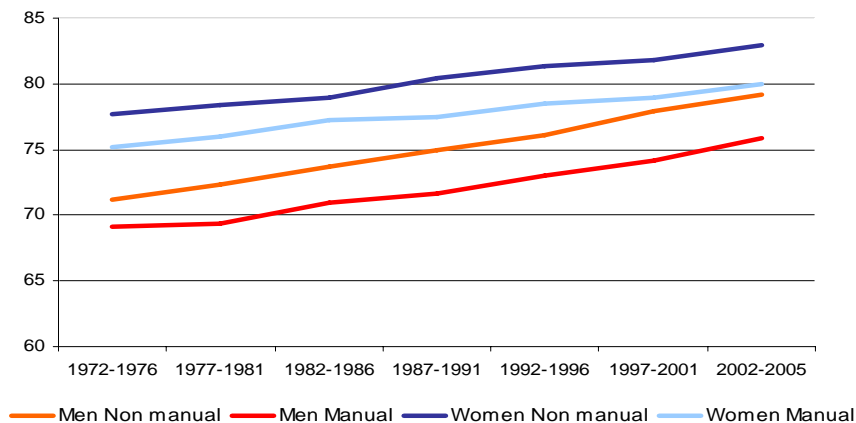


- NHS waiting times are now the shortest they have been since NHS records began. The average wait for inpatient treatment is now 4.5 weeks compared with 13 weeks in 1997. The 18-week target was achieved early at a national level and is now routinely met across the NHS<sup>6</sup>
- More than 90% of people report they are satisfied with their primary care<sup>7</sup>
- 99% of the population are registered with a GP<sup>8</sup>
- Spending on the NHS has more than doubled in real terms in the last decade and the workforce is at its highest ever level – 1.4 million in 2008<sup>9</sup>

# However, closing the gap in health inequalities requires outcomes for the most disadvantaged to improve faster than for the most advantaged

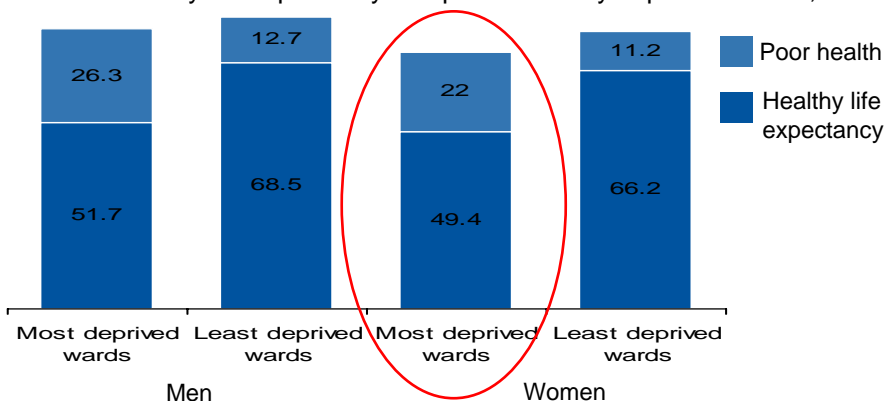
## Although life expectancy is increasing overall, a gap between socio-economic groups persists...

Life expectancy<sup>1</sup>



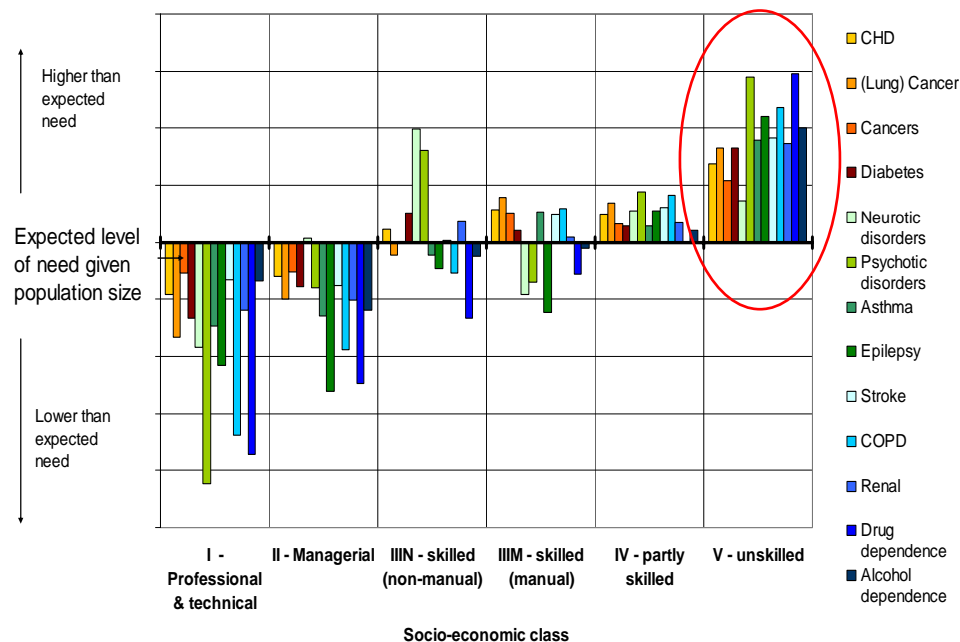
## ...with the number of healthy years life expectancy being lower amongst the most deprived wards

Years of healthy life expectancy and poor health by deprivation level, 2009<sup>2</sup>



## The lower socio-economic classes report higher than expected rates of serious health conditions

Condition by socio-economic group<sup>3</sup>



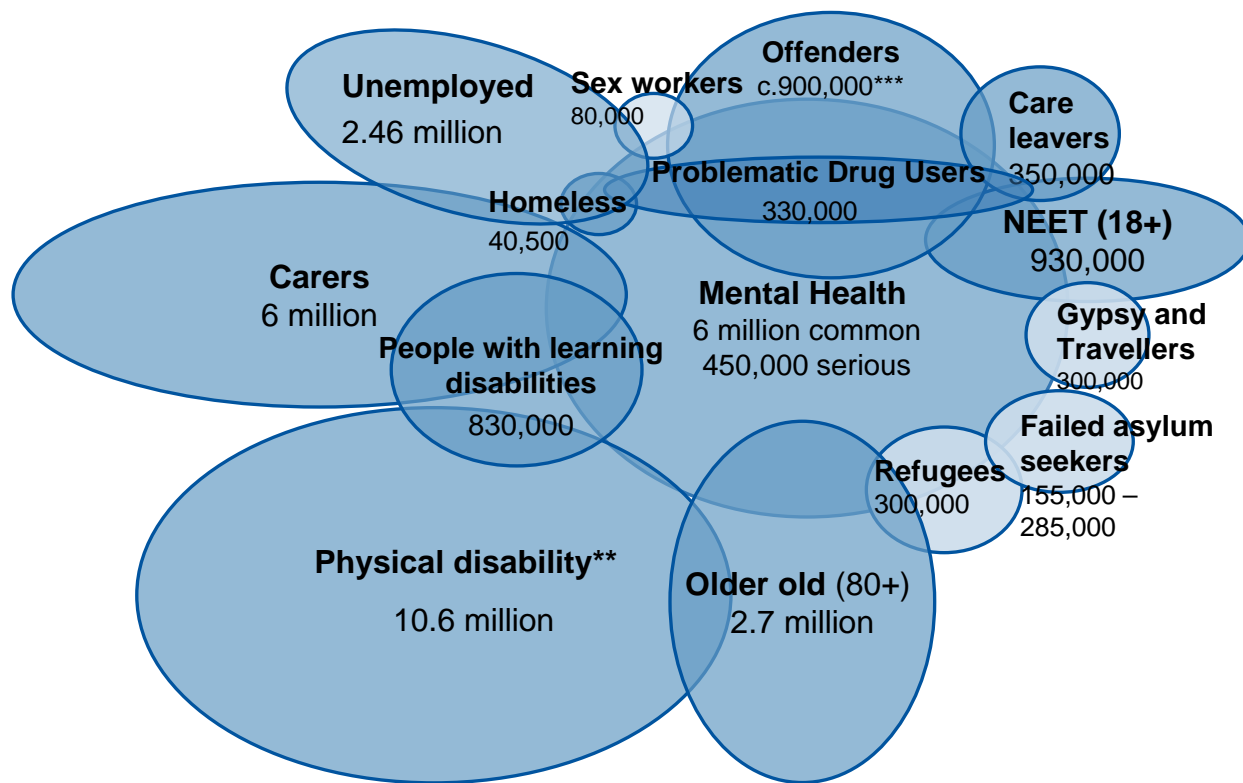
• In 2009, the Health Select Committee found that: ‘Health inequalities are not only apparent between people of different socio-economic groups – they exist between different genders, different ethnic groups, and the elderly and people suffering from mental health problems or learning disabilities also have worse health than the rest of the population’<sup>4</sup>

• However, while there is evidence pointing to the differences between groups, we know a lot less about the disparities *within* socio-economic groups and areas

# While we have some national level data on socially excluded groups, the picture is incomplete and, unsurprisingly, complex

## We know varying amounts about socially excluded groups and the socially excluded 'population' as a whole:

- Socially excluded groups are often invisible in national data sets. This may be in part because of the impact of transient lifestyles or the complexity of their problems
- We can track some of the larger and better defined groups at risk of exclusion, but there are vulnerable groups that we are unable to assess comparatively using the major surveys covering health issues
- In addition, data and research are often focussed on very specific aspects of health e.g. for migrant workers there is a predominant focus on infectious disease
- The complex overlapping nature of the groups makes it particularly difficult to get data on single groups
- There are also diversities within individual groups



Relative strength of evidence:

- Weaker evidence
- Stronger evidence

N.B. This figure is illustrative and not intended as a definitive diagram; see Annex C for more detail on the demographics of each group

\*All figures are based on the latest available data

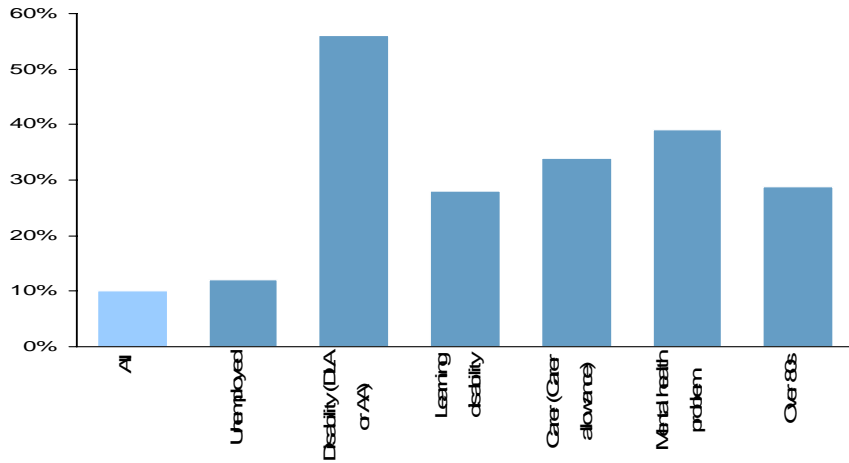
\*\*Longstanding illness, disability or infirmity

\*\*\*Figure is based on current prison population

# Available empirical data suggests that certain groups are more likely to report poorer health

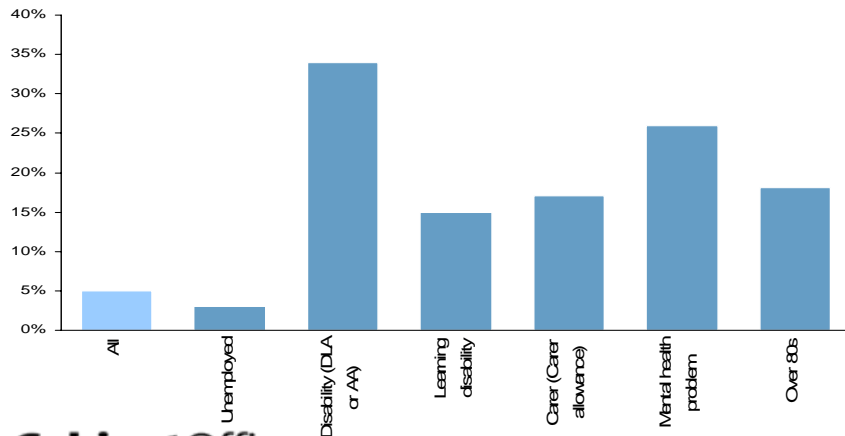
There is evidence that those in certain ‘at risk’ groups are more likely to report poor health

Reporting not good health<sup>1</sup>



Some of these groups also report higher rates of co-morbidity

Reporting 3 + limiting long term illness<sup>2</sup>



However, the picture is incomplete as national data does not cover all of the groups or show variations within groups

GHS	HSE	GP patient survey
Ethnicity (not including Gypsy and Traveller groups)	Ethnicity (not including Gypsy and Traveller groups)	Ethnicity (not including Gypsy and Traveller groups)
Unemployed (the data does not allow us to identify long term unemployed)	Rates poor general health higher among long term unemployed	Unemployed (working status)
Physical Disability (proxy disability allowance or Disability Living Allowance)	Limiting long term illness or disability	Physical disability (deaf, blind, limiting long term illness)
Carer (carer allowance)	Carer (caring responsibilities)	Carer (caring responsibilities)
Mental health problem	Mental health problem	Mental health problem
Not in education, employment or training aged 18-24	Not in education, employment or training aged 18-24	Not in education, employment or training aged 18-24
Excessive alcohol consumption	Excessive alcohol consumption	N/A
Oldest Old (proxy over 80s)	Oldest Old (proxy over 80s)	Oldest Old

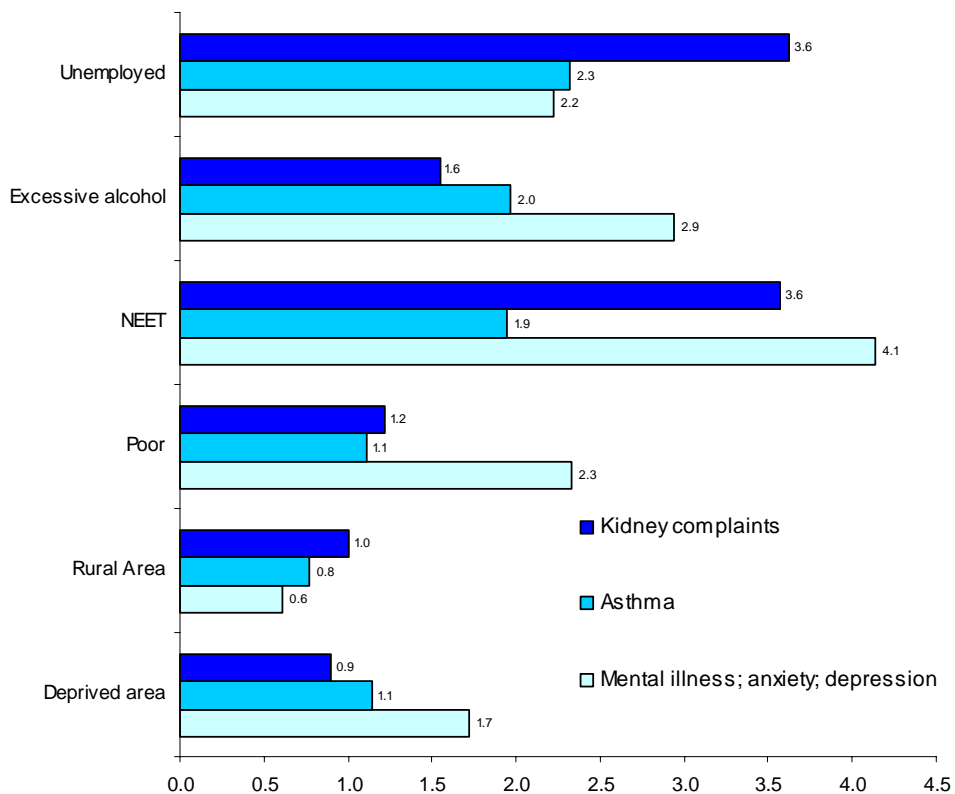
- Within the national health surveys (HSE) – the General Household Survey (GHS), the Health Survey of England and the DH GP patient survey – there are few questions which help identify socially excluded groups, while NHS hospital episode statistics only record the age, ethnicity and place of residence of patients
- It is also unlikely that the samples of people questioned include the hardest to reach, most mobile and vulnerable groups e.g. the GP survey is sent only to those already registered at a GP practice
- National surveys are not sophisticated enough to capture variations *within* groups



# Overall, the available evidence highlights poor health outcomes across the groups and a high rate of certain conditions

Across nearly all of the groups, there is evidence of poor health outcomes on a range of indicators including self reported health, life expectancy and morbidity – there are, however, ranges in both the severity of poor health outcomes, and diversity of health outcomes within groups.

Odds ratio of selected conditions by groups<sup>1</sup>



- Homeless people have higher rates of tuberculosis (TB), bronchitis, foot problems and infections than the general population<sup>2</sup>
- Alcohol misuse is identified as a causal factor in more than 60 medical conditions, including mouth, throat, stomach, liver and breast cancers, hypersensitive disease, cirrhosis and depression<sup>3</sup>
- High rates of diabetes are reported across all non-white ethno-religious minorities<sup>4</sup>
- Hepatitis B and C infection rates among female prisoners are 40 and 28 times higher than in the general population<sup>5</sup>
- Two thirds of refugees/asylum seekers have experienced anxiety or depression<sup>6</sup>
- 22% and 34% of Gypsies and Travellers reported having asthma or chest pain compared to 5% and 22% of the general population<sup>7</sup>
- 68% of women in prostitution meet the criteria for Post Traumatic Stress Disorder, in the same range as victims of torture and combat veterans undergoing treatment<sup>8</sup>
- Around one person in three with a learning disability is obese, compared with one in five of the general population<sup>9</sup>

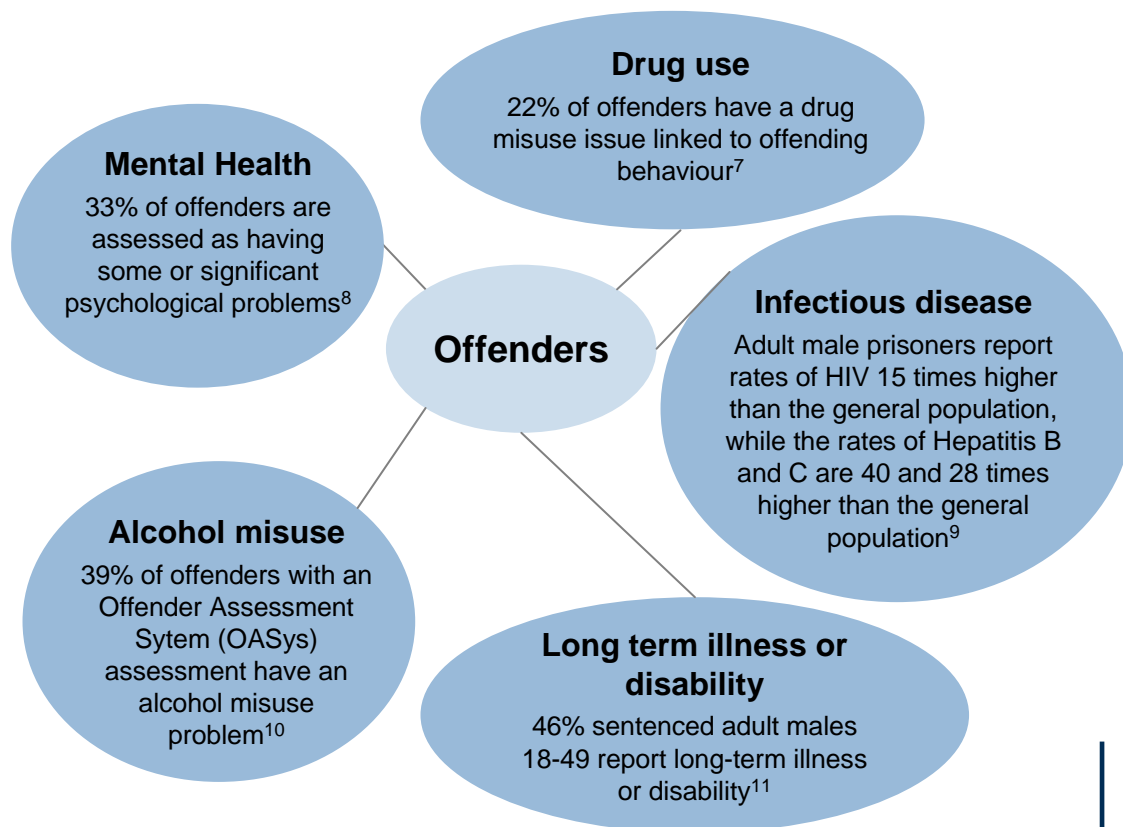
# Health needs of socially excluded groups are wide-ranging, generally high and related to the complexity and nature of exclusion

Some conditions/pathologies are reported as being particularly severe for certain groups...

Condition	Example of evidence
Tuberculosis	High prevalence of latent TB amongst homeless <sup>1</sup>
Hepatitis C	A considerable proportion of problematic drug users have chronic physical health problems such as Hep C and cardiovascular pathologies <sup>2</sup>
Respiratory problems	Self reported chest pain and respiratory problems are more prevalent in traveller population compared to a similarly deprived comparator sample <sup>3</sup>
Diabetes	Alcohol misusers are more likely to suffer from diabetes than those not misusing alcohol <sup>4</sup>
Injuries from violence	63% of women in prostitution experience violence <sup>5</sup>
Depression	Being in care leads to 20% higher likelihood of depression at age 33 <sup>6</sup>

...with many groups experiencing multiple and complex health needs

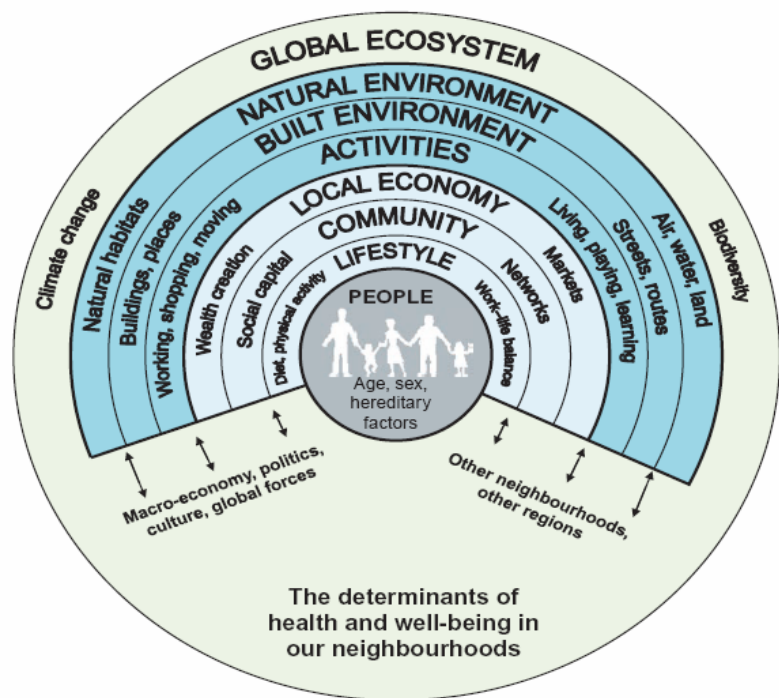
- Experiencing multiple disadvantage or problems can increase the likelihood of further problems
- From the available data, several groups are known to be at risk of experiencing a cluster of health needs:



# Social factors affect health outcomes and health equity

## Social factors can both drive and compound poor health...

The determinants of health and wellbeing (Barton and Grant, 2006)



- There is strong evidence about the cumulative effect of disadvantage across the life-course on the social patterning of disease (Marmot, 2010)
- Analysis highlights the fundamental importance of family and the intergenerational cycle to health outcomes

## ...with the effects often being particularly acute for socially excluded groups

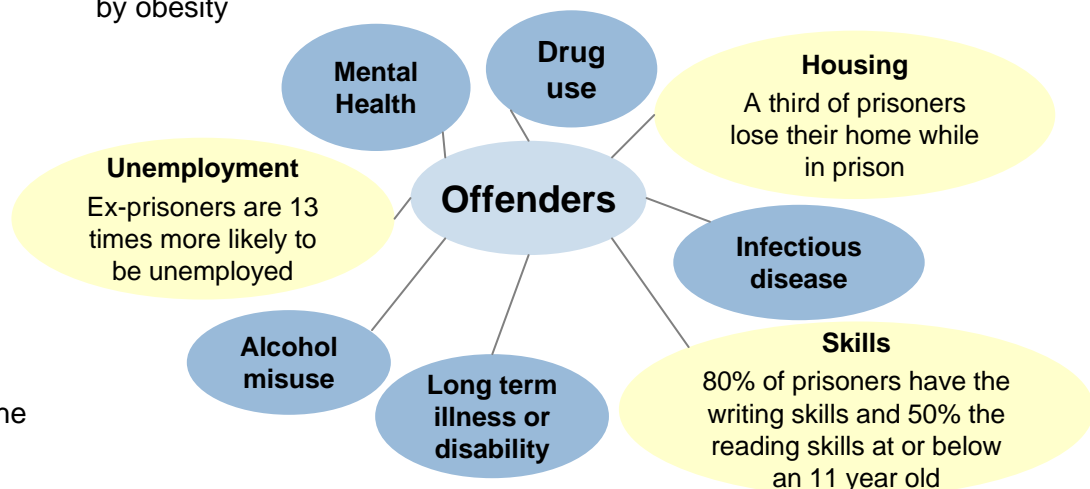
**Income** e.g. disabled people are more likely to experience income poverty and material hardship than the population overall

**Employment** e.g. employment rates of those with a long-standing diagnosis of schizophrenia or other psychosis are only 5-20% compared to 70% in the general population

**Education and skills** e.g. just over one third (37%) of homeless people do not have any formal qualifications. This is almost three times the national average of 13% of the adult population

**Housing** e.g. 30% of people living in council rented accommodation reported a limiting long-term illness (LLTI) compared with 22% of those residing in privately rented or rent free accommodation and just 14% of owner occupiers

**Lifestyle behaviours** e.g. certain minority ethnic groups and people with a mental health condition or physical disability are disproportionately affected by obesity



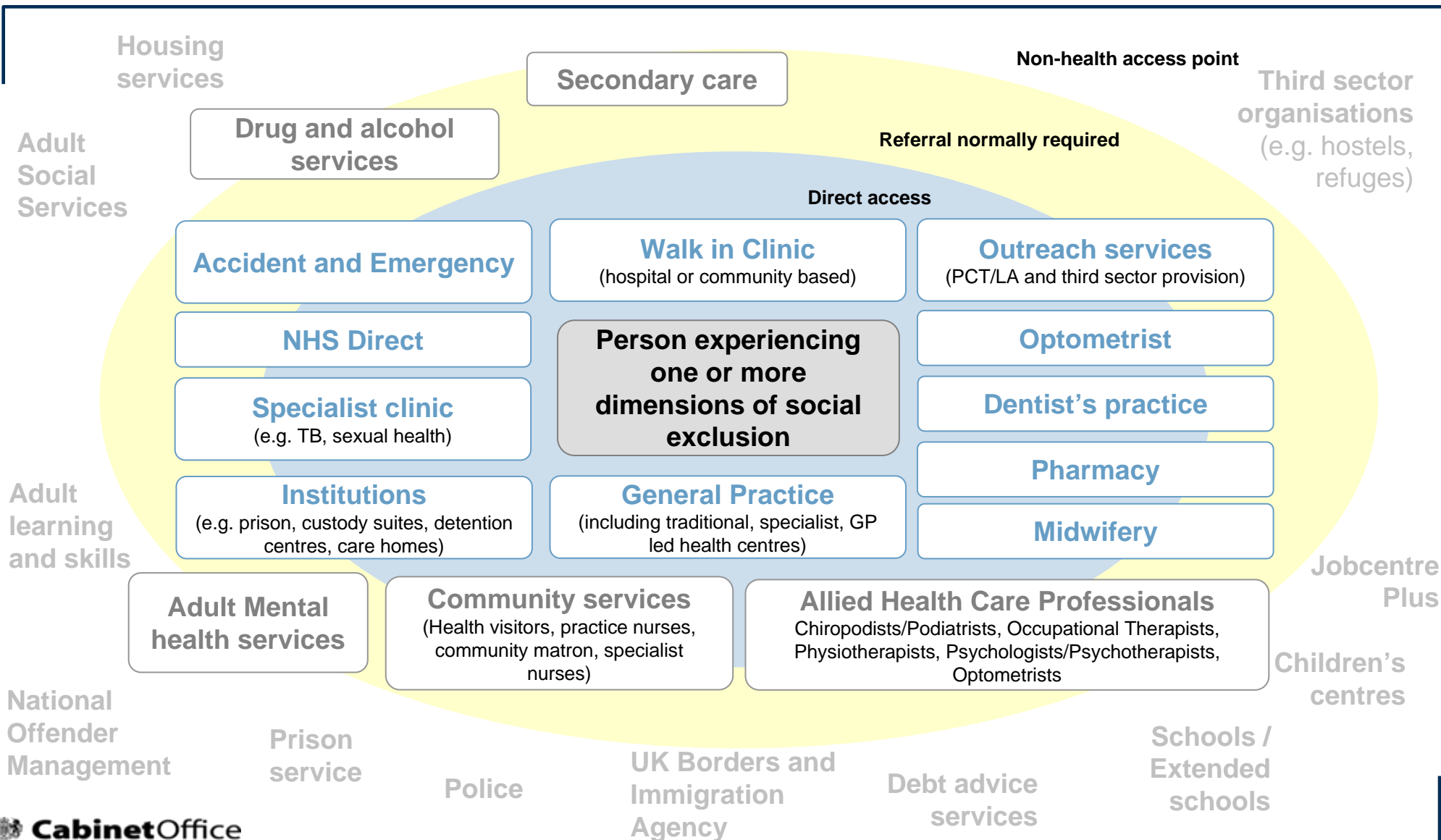
**Unemployment**  
Ex-prisoners are 13 times more likely to be unemployed

**Housing**  
A third of prisoners lose their home while in prison

**Infectious disease**

**Skills**  
80% of prisoners have the writing skills and 50% the reading skills at or below an 11 year old

# There are multiple points of contact with the system



# Experience of access varies according to complexity of need and circumstance

There are no definitive statistics on access to health care for socially excluded people. The literature indicates that points of access and service usage vary according to group, and the level and complexity of need.

## Walk in Clinic

- The majority of drug misusers engage with drop in centres<sup>1</sup>

## A&E

- 21,213 attendances at A&E for social problems (including chronic alcoholism) 2007/08<sup>2</sup>

## NHS Direct

- Substantial under use of NHS Direct by non English-speaking callers<sup>3</sup>

## Specialist clinics

- There was three times the delay to diagnosis of TB in cases detected passively compared to those detected using a Mobile X-ray Unit for hard to reach groups<sup>4</sup>

## Institutions

- On admission to prison 40% of prisoners deny contact with a GP. On release, 50% of prisoners are not registered with a GP and 42% have no fixed abode<sup>5</sup>

## Community services

- Those with the highest incomes are more likely to seek support from health visitors than lower income groups<sup>6</sup>

## Outreach services

- 31 of 125 PCTs surveyed operate an outreach team for homeless people<sup>7</sup>

## General Practice

- Around 1% of population not registered with a GP<sup>8</sup>
- Primary care is very often the first point of contact with services for carers but support is variable<sup>9</sup>
- Over 50% of households in villages and hamlets in sparse rural areas are more than 4km from a GP or a NHS dentist<sup>10</sup>
- 9 out of 10 adults with mental health problems (and a quarter of those with severe mental health problems) receive all their support from primary care<sup>11</sup>

## Midwifery

- A Healthcare Commission survey of 26,325 women found 42% of trusts had no access to a specialist perinatal mental health service.<sup>12</sup>
- The most significant shortfall in the service to women of Asian and Black origin was in the antenatal phase: they were less likely to be booked within 12 weeks; felt they had less choice as to where to have their baby; and were less likely to have a scan at 20 weeks.
- Nearly two-thirds of trusts (63%) have midwives trained to support women who misused substances.

## Optometrist

- People aged over 60 accounted for the highest proportion of NHS sight tests at 44% in England in the first 6 months of 08/09 compared to adults receiving income support (10.5%), tax credit (5.9%), job seekers allowance (1.9%), holders of low income certificates (HC2) (1.1%).<sup>13</sup>
- Visual impairment is strongly linked with social and economic inequalities and there are significant gaps in the provision of primary eye care services (GP surgeries & Optometrists) in deprived areas<sup>14</sup>

## Dentist

- Only 49% of the adult population were seen by an NHS dentist in the past year.<sup>15</sup> People in deprived areas are much less likely to be registered with a dentist and to attend for regular check ups<sup>16</sup>
- Charges mean that those on low income, particularly older people, are deterred from seeking dental care<sup>17</sup>

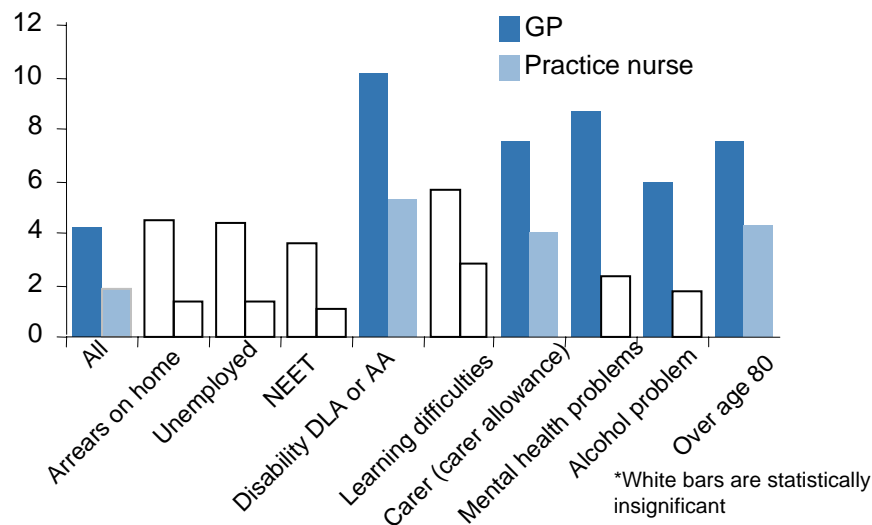
## Pharmacy

- Lower socio-economic groups are less likely to seek advice and less likely to use over the counter<sup>18</sup>
- Needs of BME groups are rarely studied but there is some evidence to suggest they use pharmacies less<sup>19</sup>

## There is mixed evidence about the different patterns of primary care usage, with differences both *between* and *within* groups

### Contact with GPs varies hugely between groups, with evidence of both particularly high and low usage...

Annual number of consultations (GHS 2006)\*



- Data from the GHS suggests some socially excluded groups consult their GP and practice nurses more regularly than the general population

- However, there is also evidence that some vulnerable groups under-utilise mainstream primary care and community services: only 67% of frequent movers (5+ moves) found it easy to access a GP compared to 74% of all 'New Deal for Communities' residents, while street homeless people are 40 times more likely than the general population not to be registered with a GP.<sup>1</sup> Evidence gathered by the Social Exclusion Unit in 2005 suggests that for every point down a seven-point scale of deprivation, GPs spend 3.4% less time with their patient

### ...and there is evidence of high rates of emergency care among certain socially excluded groups

- Homeless people are estimated to consume 8 times more hospital inpatient services than the general population of similar age and make 5 times more A&E visits<sup>2</sup>
- Gypsies and Travellers are reported to be more likely to visit A&E than a GP because of issues of trust<sup>3</sup>
- Alcohol misuse is associated with 190,000 hospital admissions each year. Around 70% of A&E attendances between midnight and 5am on weekend nights are alcohol-related<sup>4</sup>



Further analysis is required to understand the relationship between patterns of access for particular groups and the number and severity of their needs.

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## There are a range of challenges and opportunities in the system

Our analysis considered the challenges and opportunities in the system from a range of perspectives:

1. Clients
2. Practitioners
3. Providers
4. Commissioners
5. Strategic leadership

To achieve improved health outcomes for the socially excluded, we need to understand the issues across and between the various 'layers' of the system, and identify and build on the opportunities that exist.

The objectives of Inclusion Health cut across every layer of this system.





# Clients

	Where it is working well...	Where there are still challenges...
Experience and ability to navigate system	<p><b>Clients and professionals are effectively accessing appropriate and continuous primary care</b></p> <p>Clients require accurate and clear information, along with support to access and navigate care. There are promising examples of Third Sector advocacy and facilitation. For example, the Elfrida Society's <i>Access to Health</i> project provides support to people with learning disabilities, helping them overcome difficulties in understanding medical terminology, and accompanying them to appointments and making complaints when necessary. Promising practice ranges from having clear information in one place (such as the NHS Dental services leaflets for homeless people in London) to the use of social marketing techniques and user engagement to develop information which really talks to users. For example, the Pearl Service (Chelsea and Westminster NHS Foundation Trust) is a dedicated and innovative easy access sexual health service for people with learning disabilities. At the Pearl Service clients are met on arrival by a sexual health adviser, and supported throughout the entire sexual health process from registration and screening to obtaining results. The service uses specially designed and written literature, photos and pictures to aid comprehension.</p>	<p><b>Many clients lack experience of using primary care, and their chaotic lifestyles and complexity of need can make it difficult to access and navigate systems</b></p> <p>Professionals at every layer of the system need to be sensitive to barriers related to language and regulations.<sup>1</sup> In addition to presenting with complex needs, clients with chaotic lives may have a history of behavioural difficulties (e.g. poor impulse control, extreme self-neglect) and abuse (e.g. child abuse, regular victims of violent crime)<sup>2</sup> – factors which impact on their capacity to get the best possible primary care. In addition groups may not fit the eligibility criteria of services, either because their level of specific need is not high enough, or because they are disqualified/ineligible due to specific problems (e.g. drinking or drug taking). Dual diagnosis can be a barrier to treatment – “<i>mental health services too readily exclude people with drugs and alcohol problems</i>”.<sup>3</sup> In some of the worst cases, socially excluded patients may have exhausted formal services to the point where they are explicitly banned.</p>
Trusted relationships	<p><b>Clients have trusted and respectful relationships with professionals</b></p> <p>Voluntary organisations often maintain credibility where client groups find it hard to form trusted relationships within mainstream public services. For example, the Southwark Travellers Action Group use peer workers to engage Gypsy, Roma, Travellers and the Leicester Pacesetters Health Ambassador programme reaches out to clients through members of their communities and a specialist health visitor. Another promising example is the strengths-based approach of the Family Nurse Partnership programme, which is based on building up understanding and respect between professional and client.</p>	<p><b>Client groups can feel invisible or stigmatised and find it hard to build trusted relationships</b></p> <p>During the focus groups, clients reported that their decision to access healthcare through A&amp;E was in part owing to the neutrality of the service – “<i>you don't necessarily stand out</i>” (SETF fieldwork, 2009). Practitioners reported that hours of positive engagement can be easily lost through a client's bad experience: “<i>a ten minute consultation could so easily set back all the great work that others had done in the previous two years to get the person to see me in the first place</i>” – (GP practitioner, SETF roundtable).</p>
Health aspirations and choice	<p><b>Socially excluded clients are empowered to take control of their care and lead healthy lives</b></p> <p>For example, the Friends Families and Travellers Health Project Voluntary Group is an informal group which helps the Gypsy and Traveller community identify health issues and raises awareness about health entitlements. The NHS Health Training initiative (launched in 2005) has reached over 60,000 people. Nearly 90% of PCTs have a health trainer service. Nearly half of health trainer clients are drawn from the 20% most deprived communities in the country. Two thirds of clients fall within one or more deprivation indicators.</p>	<p><b>Many socially excluded people have low health aspirations, poor expectations of services and get little opportunity to shape their care</b></p> <p>Many individuals face great hardship and have more urgent challenges than their immediate or long-term health. For example, research suggests that homeless people may place a low value on health generally in the face of poverty and their day-to-day difficulties; “<i>I was on a destructive streak; I did a lot of bad things to myself and didn't know how to deal with it... I was kinda going to all these doctors... but I'm kinda disillusioned with the health care you know</i>” (Martin, 22, homeless; SETF fieldwork, 2009).</p>

# Workforce/practitioners

	Where it is working well...	Where there are still challenges...
Skills, awareness and support	<p><b>Professionals are switched onto the specificity of socially excluded clients' needs and appropriately supported</b></p> <p>This might include examples of recognising the key role that every member of the workforce can play in enabling patients to make choices. For example, the Bromley-by-Bow Centre has aimed to turn receptionists into 'gate openers', ensuring that they play a fundamental role in the clinical team. To this end, receptionists are appropriately updated on individual patient's circumstances, needs and behaviour. The multi-disciplinary team at Praed Street are switched onto the specific needs of sex workers and take a 'whole person' and family approach to their care. Formal and informal support structures and networks, such as the Queens' Nursing Institute Homeless Health Initiative, can be a valuable way of bringing together and supporting mainstream and specialist practitioners who work in this often stressful and challenging field.</p>	<p><b>Practitioners can lack the skills and awareness to effectively engage and deal with excluded clients</b></p> <p>Practitioners consistently cite complex caseloads, challenging clients and sometimes poor physical working environments. A poll published in the 2002 Audit Commission report showed that only a quarter of GPs felt confident working with opiate mis-users. The Queen's Nursing Institute (QNI) survey of its members found practitioners reported lacking the information, skills and confidence to support some clients e.g. 71% of non Homeless Health Specialists were not confident in their ability to care for homeless people. The QNI survey data found that 74% of respondents are lone workers always, often or sometimes; and 85% of those who felt isolated were Homeless Health Specialists.<sup>1</sup></p> <p><i>"I feel as if my doctor does not know what I am going through... what I was experiencing... if he doesn't know what I am going through then it's like the blind leading the blind..."</i> (Martin, 22, homeless; SETF fieldwork, 2009)</p>
Diagnosis and treatment	<p><b>Clients are rapidly diagnosed and hooked into treatment</b></p> <p>Diagnosing problems quickly and thoroughly is critical as chaotic clients can have sporadic contact with services. It is therefore important that practitioners understand service 'touch-points', and make the most of the contact they have with their clients. For example, the Mobile X-Ray Unit (MXU) provides a mobile tuberculosis screening service that visits London's homeless hostels and prisons. The service reaches out to engage clients and can identify TB infections within a few minutes. Clients are then taken directly to one of London's specialist TB clinics and hooked into treatment. Targeted MXU screening of hard to reach groups substantially reduces delays in diagnosis and infectivity and is therefore likely to make a significant impact on disease transmission. Cases identified through screening also can result in less severe disease.</p>	<p><b>Practitioners may treat presenting symptoms rather than addressing underlying causes and supporting recovery and sustained behaviour change</b></p> <p>Clients with co-morbidity tend to become viewed as everyone's problem but no-one's particular responsibility. When engagement with service users is ineffective they can end up bouncing from service to service. The inability to deal effectively with an underlying problem can result in clients making repeated visits to A&amp;E. Whilst the diagnosis of underlying problems may take more resource at initial stages of contact with the clients, it can, in the longer-term, prove cost-effective.</p> <p><i>"Not only can it be difficult to meet a range of needs, but there can be pressure to close cases too early, especially when clients do not turn up"</i> (Health practitioner; SETF fieldwork 2009).</p>
Information	<p><b>Accurate and timely data is appropriately shared</b></p> <p>It is critical to have accurate and up-to-date information on the clients health and wider needs and circumstances, which is shared appropriately with both the client and other services. The new summary care record (SCR) service and electronic prescription services (EPS) have the potential to connect providers in better enabling the continuity of care and outcomes that people who lead chaotic lives need. Information sharing protocols and common assessment processes can ensure a seamless service for the hardest to reach. It is also important to share information on the availability and quality of services to enable patient choice.</p>	<p><b>Recorded information can be variable in quality and quantity, and poorly shared amongst professionals and across disciplines</b></p> <p>The QNI survey found that only 40% of survey respondents used Standardised Health Needs Assessments, while only 49.5% of respondents stated that they used computerised medical records.<sup>2</sup> Poor understanding of confidentiality clauses should not be a barrier to sharing information. Services must strive for consensus on what and how information can best be shared in order to improve outcomes for the most excluded. The NHS Constitution is an important tool in aiding clients and practitioners to understand their rights and responsibilities.</p>

# Providers

	Where it is working well...	Where there are still challenges...
Service design	<p><b>Promising practice is out there</b> There are examples of innovative responses to local problems. For example, Hammersmith and Fulham PCT and Charing Cross Hospital have worked together to set up a social enterprise model of primary care based on the A&amp;E site. In Billericay, Essex, a nurse-led practice set up to meet the needs of the socially excluded groups has developed into a mixed specialist and mainstream primary care provider taking patients from a wide area. Models range from mainstream to specialist, clinical to social, and are delivered by a range of providers. The most effective shared a set of common characteristics (see page 67) However, successful approaches are likely to require an integrated approach to service provision, and may involve a combination of adapting 'mainstream' services to better meet the needs of these people, together with developing and supporting specialist provision.</p>	<p><b>There is an artificial divide between clinical and social models of care</b> Practitioners and managers report an artificial divide between clinical and social models of care, and often experience disjointed working between specialist and mainstream services. In some areas where there are clear concentrations of particular client groups, commissioners are supporting the establishment of specialist provision. However, in several sites practitioners and clients reported that surrounding primary care providers were frequently willing to refer clients, but much less willing to take them back into their services. This left the services 'siloe'd' and patients without the support to return to mainstream care. <i>"There is no point in having primary care solutions without having the other services there"</i> (primary health care provider, SETF fieldwork, 2009)</p>
Evaluation	<p><b>There is recognition of the need to build an evidence base</b> In many cases, services are recognising the need for a stronger evidence base and developing ways to achieve this. Where it is working well, a mix of methods are used. In some promising examples, clients are invited to feedback and shape their service. For example a specific target of the Walsall Integrated Learning Disability team, is to reduce deaths from breast cancer among women with learning disabilities by making screening services more accessible. A key element of the team's approach has been to involve users in shaping and implementing the project. A 'buddying' system was set up to ensure their voice was heard and health information redesigned. Users say the project has helped to remove their fear of mainstream services.</p>	<p><b>There is a limited evidence base on what works for socially excluded clients, and services lack the capacity to evaluate</b> Providers can lack the capacity/capability to properly evaluate their service. There are few outcomes-based approaches to commissioning, and owing to the size of service and client groups, it can be difficult to reach sufficient numbers to make the evaluation of services robust or meaningful. Hard to reach groups lack sufficient voice in their evaluation of services. There is value in looking to other services both within and outside primary care, such as evaluations within pharmacy and health visiting, including programmes such as the Family Nurse Partnership.</p>
Incentives	<p><b>Common goals and shared interests drive organisations to deliver</b> The 'business' case for services is vital. For example, the evaluation and cost benefit model undertaken by Turning Point for its Connected Care model, enables commissioners to benefit from the cost efficiencies of early integration and joined up services. Equally, the rationale for St Mungo's investment in provision of an intermediate care service is in part incentivised by the project's ability to prevent hospital admissions, facilitate discharge, and implement effective continuous care packages which ultimately result in potential cost savings. <i>"There is an appetite for social and moral achievement achievements to be rewarded"</i> (Senior health practitioner; SETF Fieldwork, 2009).</p>	<p><b>Lack of incentives to drive partnership working and improved outcomes</b> A lack of incentives can mean the needs of the socially excluded are of low priority, and can result in poor continuity of care. South London and Maudsley NHS Foundation Trust reported that 'one of the biggest problems we have is as clients move from Southwark into Westminster or Lambeth – it is not that there aren't good services there – it is that there is no incentive to carry on the care, and people start all over again'. <i>"Acute spending is in part controlled by primary care... In the worst services, there can be a culture of batting people away – looking for ways of blocking people who will cost a lot of money"</i> (GP, SETF fieldwork 2009).</p>
Flexibility	<p><b>Services have the flexibility to respond to the complex needs and chaotic lifestyles of their clients</b> Small changes in attitude or systems can make a big difference to access and quality of care. Flexible approaches to appointments (e.g. open slots) and registration (e.g. use of 'proxy' address) can be invaluable to chaotic clients, for example in Safe Haven and Great Chapel Street health centres. In addition, services need to be willing to work with those who may not be ready to address substance use.</p>	<p><b>Practitioners report that the greatest impediment to their work is the inflexibility of the services that they need to work with</b> Practitioners in all the study's focus groups reported that inflexibilities spanned a range of areas. Most notably, the complex needs of clients cross multiple funding streams when clients often require a holistic service. Providers may experience inflexible rules around registration requirements, information sharing, and appointment length.</p>

# Commissioners

	Where it is working well...	Where there are still challenges...
Needs assessment	<p><b>There is joint working at a local level to comprehensively assess need</b></p> <p>Holistic needs assessment, which capture the immediate health needs, wider needs, and circumstances of the client (including family) can make a real difference to the delivery of effective care. To achieve this, it is critical that services have as much information possible to inform the picture of need. One way to achieve this is through partnership with local third sector organisations. For example, Homeless Link is piloting a health needs audit tool which will enable agencies to record and evidence the health needs of their homeless clients. By using feedback from individual service users, the audit tool is a means to gather information of overall need in an area and will be used to inform commissioning of future services. In another example, Turning Point's Bolton Connected Care project used a group of 25 community researchers to contact 10% of the population aged 16+ to produce an audit report.</p>	<p><b>Clients at greatest risk tend to cluster around services or places, but do not show up on needs assessments</b></p> <p>The study found that area based approaches to Joint Strategic Needs Assessment are not always managing to pick up the most excluded client groups – yet they were not hard to find and frequently aggregate in groups or in areas. In the 2007 survey, respondents were asked about problems and barriers to involving patients and public in commissioning. Three quarters (76%) of all respondents said that “our current engagement processes don't reach ‘seldom heard’ groups”.<sup>1</sup> There are important differences between and within groups which need to be acknowledged.</p>
Collaboration and involvement	<p><b>A wide range of partners are involved in the design and delivery of services</b></p> <p>World Class Commissioning will enable the NHS to meet the changing needs of the population by developing a more strategic, long-term and community focused approach to commissioning services, where commissioners and health and care professionals work together to deliver improved local health outcomes. The most impressive solutions to meeting socially excluded groups' needs were often based upon collaborations with local knowledge partners. North East Lincolnshire PCT has engaged the Design Council in determining what service offer would be most likely to work. Liverpool's two-year cancer strategy was devised by public health professionals working with clinicians, nurses patients and carers. It also used social marketing techniques to target individual groups, such as those with mental health problems and to ascertain the best ways to communicate specific health messages to individual communities. Turning Point's Connected Care model for community led commissioning brings the voice of the community to the design and delivery of all health, housing, education and social service delivery. Reports consistently highlight that services work best when they operate as part of a network that include mental health services, especially personality disorder services, substance misuse services and accommodation services.</p>	<p><b>There is still potential for much greater collaboration with patients, public and academics</b></p> <p>There is much greater potential for PCTs and local authorities to forge links with local further education and research communities. Only 38% of PCTs responding to a Picker Institute survey said patient forums and local involvement networks had been “highly influential” in developing their patient and public engagement strategies.<sup>2</sup> In addition, PCTs and Local Authorities should be encouraged to collaborate with patients, including the hardest to reach. “Community engagement” is a guiding principle of Liverpool's (joint City Council and PCT) JSNA process. However, this promising practice approach is not necessarily replicated in other areas of the country. “<i>This is about transforming the way people think about working together</i>” (Senior commissioner; SETF fieldwork 2009).</p>
Prevention and health promotion	<p><b>Early intervention and health promotion is being targeted at the hard to reach</b></p> <p>World Class Commissioning will support the shift from treatment and diagnosis to prevention and the promotion of wellbeing. This is crucial for delivering a fair health service as lifestyle choices are responsible for as much as half of the gap in health outcomes. Some organisations are providing support to halt the escalation of problems (such as intermediate care services to prevent hospital admissions, at St Mungo's Cedar's Road hostel and the Homeless Health Project UCLH) and some areas are targeting specific interventions at vulnerable groups (e.g. the Healthy Towns Programme, which targets low-income groups and aims to tackle obesity by increasing knowledge of healthy choices; and Luton Change for Life campaign, which aims to engage and empower individuals to seek their own life style changes).</p>	<p><b>There is limited focus on health promotion, prevention and recovery</b></p> <p>Despite evidence suggesting that many socially excluded groups are amenable to the health promotion and preventative measures, there is an insufficient focus on prevention. Hard to reach groups can easily fall under the radar and miss out on screening and health and wellbeing initiatives. For example, evidence from existing colorectal cancer screening programmes indicates lower participation among minority ethnic groups than the white-British population.</p>

# Leadership/strategy

	Where it is working well...	Where there are still challenges...
Status and prioritisation	<p><b>There is prominent and clear local leadership as well as visible commitment</b></p> <p>Prominent and clear local leadership at the highest level, including Board sign up, greatly enhances the likelihood of a successful approach to improving access to primary care services for the socially excluded. The study found the best solutions, whether at PCT level, with acute providers or across the Third Sector, were achieved when committed visible leadership supported this as a priority. For example, Liverpool's drive to Tackle Health Inequalities is underpinned by successful joint working and clear leadership and driven through a rolling programme of work under the Better Together banner. The clear vision and aim for Tackling Tobacco and Smoking in Liverpool (Tobacco Control Strategy 2008-2011) are driven by joint commitments from the chair of the PCT, Leader of City Council and Director of Public Health. It is currently leading a European Tobacco Control Network to protect children and young people from smoking and exposure to second-hand smoke.</p>	<p><b>Health care for socially excluded groups can be of low priority and vulnerable groups are not sufficiently at the forefront of health strategies and planning</b></p> <p>The most vulnerable citizens are often in greatest need of public services. If we enable a primary care landscape that meets socially excluded groups' needs, it will almost certainly be more focussed on achieving better outcomes for all. Stability of leadership teams is critical, as is clarity on objective and purpose. Some organisations have taken the active step to specify whether they were commissioning for socially excluded groups <i>as well as</i> mainstream users. However, we need to ensure that all boards are putting in place clear and transparent criteria around socially excluded groups where there is a need. Lack of voice and advocacy means that often leaders and managers struggle to compete for scarce resource alongside alternative (and often more popular and well mobilised) causes. Organisations are working hard to ensure that users and professionals who work in this challenging field are given sufficient voice (for example the Homeless Health Initiatives), however it can be difficult to be heard in the current climate. In addition to the moral case for improving primary health care for socially excluded groups, there is emerging evidence that it makes economic sense to invest in improved services, and this can be a compelling case to raise the status of this agenda (see pages 69-74)</p>
Health and wellbeing outcomes	<p><b>Socially excluded groups benefit from policies and programmes to improve their overall health and wellbeing</b></p> <p>Over the past decade, reforms have led to improved outcomes for the population at large e.g. rising life expectancy, falling infant mortality, reduced waiting times. There are a number of evidence-based programmes such as Family Nurse Partnership, which targets disadvantaged groups and have been demonstrated to deliver positive cost-effective outcomes that can help transform the life chances of those involved. Targeted support structures (such as the National Support Team for Inequalities) are increasing understanding of how by successfully addressing inequalities we can also assist in the delivery of other targets such as reducing premature deaths from health disease, stroke and cancer, reducing smoking prevalence and halting the rise in obesity. Initiatives such as Liverpool's Big Health Debate can drive a focus on health and wellbeing, even in the hardest to reach communities.</p>	<p><b>Socially excluded groups continue to fall under the radar, and health and wellbeing outcomes do not adequately reflect the specificity and complexity of their needs and circumstances</b></p> <p>Current system drivers such as the GP practice questionnaire, the Quality and Outcomes Framework and current indicator sets do not effectively report the outcomes of socially excluded groups. Consequently, the health and wellbeing outcomes of the hard to reach are ineffectively measured and managed. Health outcomes achievable by people with complex and challenging health and care needs are by nature difficult to describe. There can be challenges around agreeing definitions of 'at risk' and 'in need'. It can also be difficult to capture whether people's engagement with a service has been sensitive to their need and circumstance, and challenging to track the stabilisation and longer-term health improvements of chaotic clients.</p>

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**Annexes**

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# Sex workers: demographics

## Definition

- 'Sex work' refers to the exchange of sexual services for some form of payment, usually money or drugs.<sup>1</sup> For the purposes of this project, we are excluding activities where no physical or intimate contact takes place, such as telephone sex.
- Professionals emphasise the importance of the distinction between 'street-based' and 'off-street' prostitution because of the differing nature of the work, the risks and needs of the groups involved. Where possible, we have sought to make this distinction clear in the data presented.

## Demographics

**Population:** Although ten years out of date, the most commonly used data estimates that there are 80,000 sex workers in the UK.<sup>2</sup> Estimates suggest that, of the 50-80,000 *female* sex workers, around 28% work in street prostitution, while the remaining 72% work in indoor establishments and as escorts.<sup>3</sup> An estimated 4,000 women were trafficked into the UK in 2003.<sup>4</sup>

**Gender and age:** The majority of sex workers are women and most are young (on average, 25-27). It is also estimated that up to 5,000 children may be involved in prostitution at any one time.<sup>5</sup>

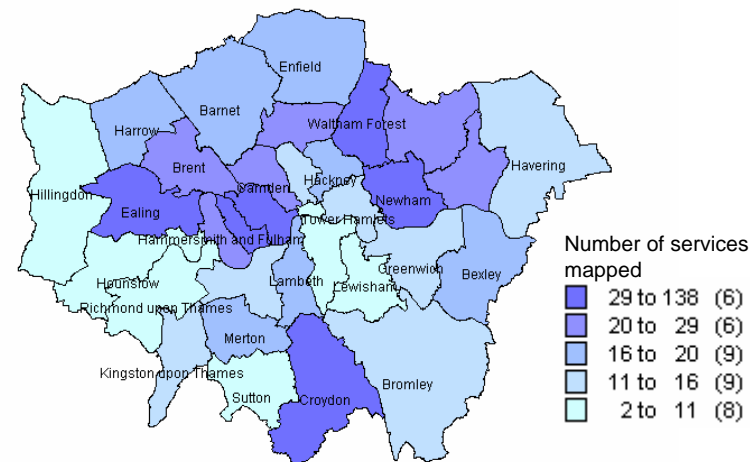
**Nationality and ethnicity:** The nationality and ethnicity of sex workers varies considerably between areas. In London, a 2003 mapping exercise found that only 19% of women came from the United Kingdom, while 25% were from Eastern Europe, 13% from South East Asia, 12% from Western Europe and 2% from Africa. By contrast, research in Bristol found that most women were from the UK and that 83% of both parlour and street workers were white European, with approximately 10% from black ethnic groups.<sup>6</sup>

**Families and relationships:** Home Office evaluation found that 49% of female sex workers had at least one child, while women were almost twice as likely to be living away from their children as with them.<sup>7</sup> A study in Bristol found that 61% of street workers had children under 16.<sup>8</sup>

There has been a significant change in the profile of sex workers in the UK over the last 20 years:

- Sex workers are more likely to work indoors, in flats and to advertise on the internet and through the adult entertainment industry
- Since the mid 1990s, the proportion of UK-origin sex workers has fallen and those of non-European origin has increased, coming primarily from Eastern Europe, the former Soviet Union, and developing countries in Asia, South America and Africa

In 2003, the POPPY Project mapped the coverage of Sexual Health Outreach Services in London, by borough (2003)



The study found 730 flats, parlours and saunas to be selling sex, with every London borough having off-street prostitution. Westminster has the largest density with 138 flats/parlours/saunas. Other London boroughs have an average of 18.5 sites selling sex. On-street prostitution was discovered in 10 boroughs.

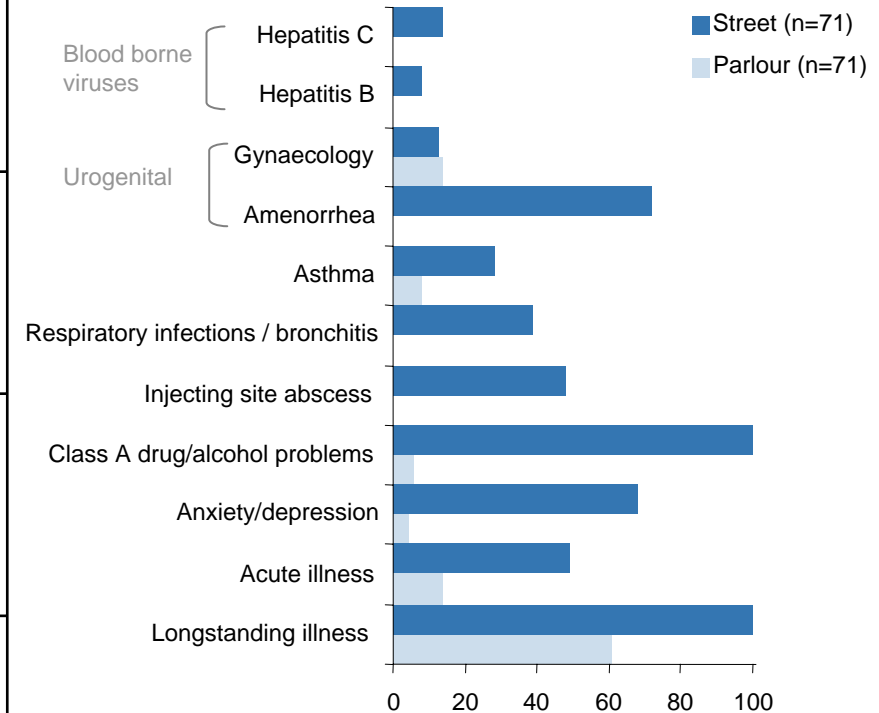
# Sex workers: health needs and outcomes

## Commercial sex workers are likely to experience poor health because of the risks associated with their work

Health risks	Supporting evidence
Violence	<ul style="list-style-type: none"> <li>• More than half of UK women in prostitution have been raped and/or seriously sexually assaulted. At least three-quarters have been physically assaulted<sup>1</sup></li> <li>• Outdoor working is associated with higher levels of violence by clients, with half of sex workers reporting experiencing violence in the six month-period prior to being interviewed<sup>2</sup></li> <li>• Women in prostitution in London suffer from a mortality rate that is 12 times the national average<sup>3</sup></li> </ul>
Substance misuse	<ul style="list-style-type: none"> <li>• Up to 95% of women in prostitution are problematic drug users<sup>4</sup></li> <li>• Drugs are more likely to be a problem or the main cause of prostitution in street sex markets, with 85% of workers reporting using heroin and 87% using crack cocaine (compared to 6% and 7% for parlour workers). In Bristol, 96% of street workers reported using drugs every day in the last 30 days compared to 23% of parlour workers<sup>5</sup></li> </ul>
Sexual health	<ul style="list-style-type: none"> <li>• There is a large body of evidence indicating that women selling sex are at higher risk of sexually transmitted infections<sup>6</sup></li> <li>• 23% of parlour workers and 27% of street workers report having received treatment for Chlamydia (compared to 3% of the general population), 11% and 17% respectively for Gonorrhoea (0.8% gen. pop.), 6% and 11% for genital warts (1.3% gen. pop.) and 0% and 4% for syphilis (0.1% gen pop)<sup>7</sup></li> </ul>
Mental health	<ul style="list-style-type: none"> <li>• Among offenders convicted for prostitution related offences, over 48% experienced psychological problems or depression compared to 33% of other offenders<sup>8</sup></li> <li>• 68% of women in prostitution meet the criteria for Post Traumatic Stress Disorder in the same range as victims of torture and combat veterans undergoing treatment<sup>9</sup></li> </ul>

## Health outcomes and behaviours of sex workers vary considerably

Analysis highlights significant differences in the health needs of street and parlour based sex workers in Bristol<sup>10</sup>:



Source: Jeal, 2007

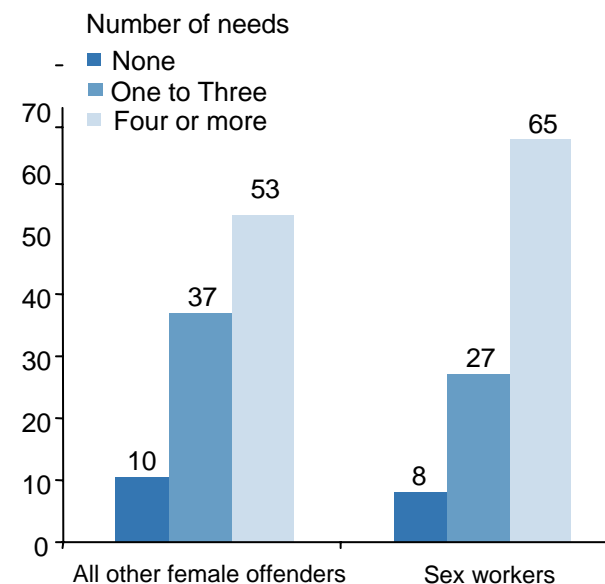


## Sex workers: wider needs

Social determinants	Supporting evidence
History of abuse	<ul style="list-style-type: none"> <li>45% report sexual abuse and 85% physical abuse within their families<sup>1</sup></li> </ul>
Income and employment	<ul style="list-style-type: none"> <li>74% of women involved in prostitution cited poverty, the need to pay household expenses and support their children, as a primary reason for entering sex work<sup>2</sup></li> <li>Street workers are more likely to work to support a drug habit. The average (median) weekly drug expenditure for street workers was £650 compared to £10 for parlour workers<sup>3</sup></li> </ul>
Education and skills	<ul style="list-style-type: none"> <li>66% of women involved in prostitution had no qualifications, and only 21% were educated to GCSE level<sup>5</sup></li> <li>Evidence from a number of studies indicates that over half of sex workers became involved in prostitution under the age of 18 (HO, 2004b – Annex C). 75% of children who become involved in prostitution have interrupted or prematurely terminated educational careers</li> </ul>
Housing	<ul style="list-style-type: none"> <li>Being homeless or living in temporary / insecure accommodation is a common issue for sex workers.<sup>6</sup> Almost two-thirds of 70 women interviewed in Liverpool had no fixed abode<sup>7</sup></li> </ul>
Offending	<ul style="list-style-type: none"> <li>Of 202 women prostitutes interviewed, nearly a third had between one and five previous convictions: the most common were for theft/handling of stolen goods (73%), prostitution related offences (47%) and fraud/forgery (31%)<sup>8</sup></li> <li>27% of women prisoners reported being paid for sex in the 6 months before entering prison and one in ten young women in custody said they had been paid for sex<sup>9</sup></li> </ul>

Jeal and Salisbury (2007) found that fewer off-street sex workers than street workers had experienced sexual abuse (22% versus 43%), that they left education later (mean age 16.6 compared to 14.9 years) and experienced much lower rates of homelessness (11% compared to 66%)<sup>10</sup>

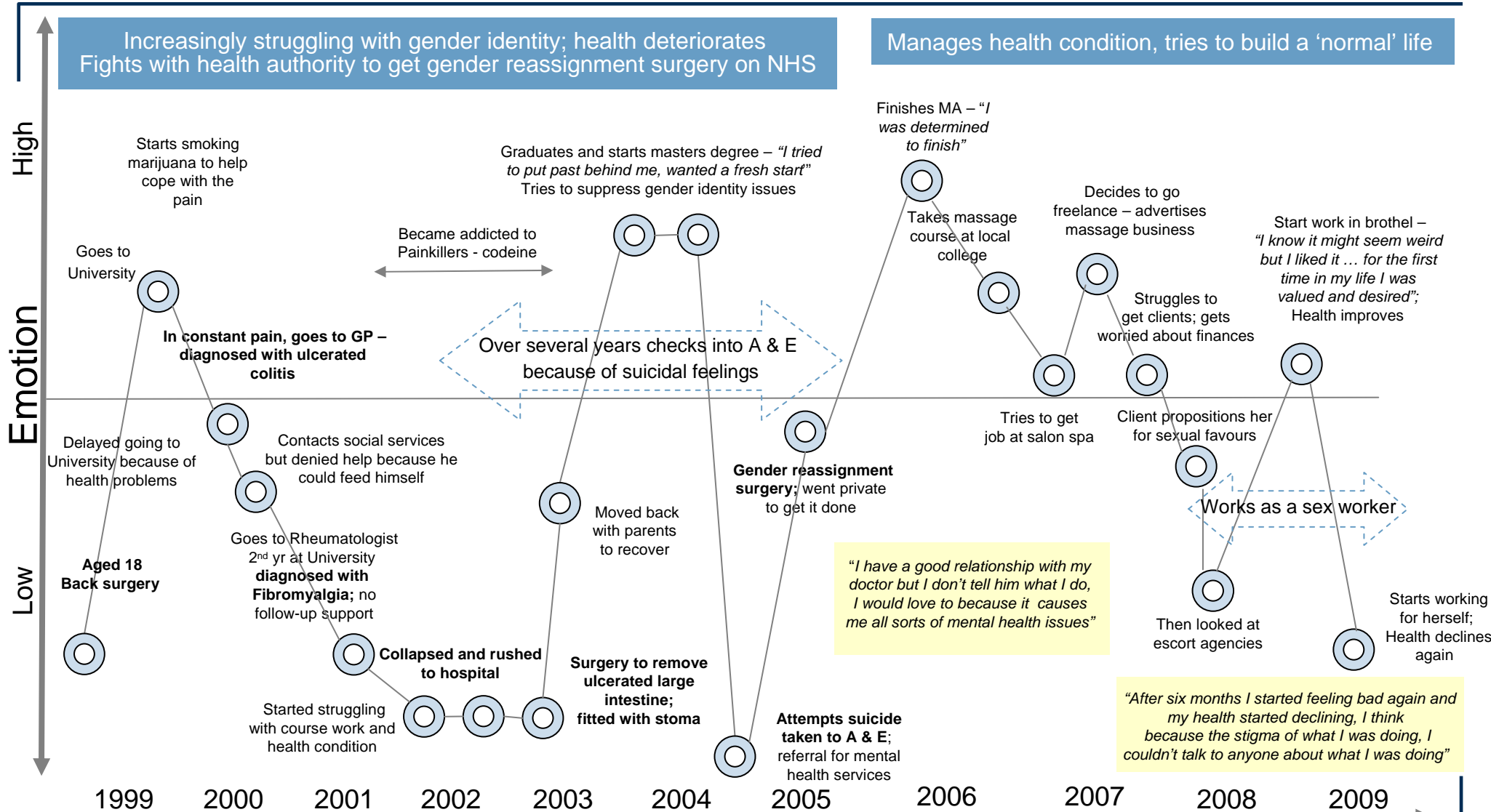
Female offenders who were sentenced for offences related to sex work prior to commencing (or at the end of) a custodial sentence were more likely to report a high number of needs (four or more) than those not sentenced for offences related to sex work.



The range of needs included a number of health related, medical and basic ones: 1) Drug and alcohol misuse; 2) Psychological problems; 3) Psychiatric problems; 4) Accommodation problems; 5) Financial issues; 6) Social Isolation Source: SETF's analysis of Home Office (2006/07) Offender Management Data (OASys) data.

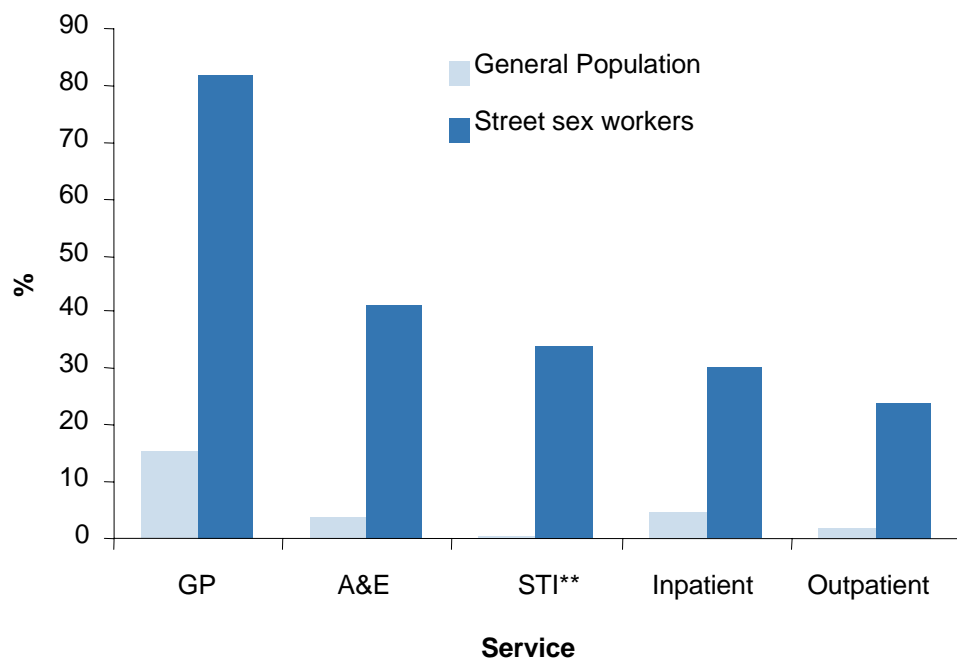
# Case study

Gina – late 20s – lacked support for long-term condition, leading to isolation and disconnection



## Sex workers: summary of access

Street sex workers have significantly higher rates of health service use\* compared to the general population



Source: Adapted from Jeal (2007) and data from the General Household Survey (GHS).  
\*Sex workers were asked about service use in the last 12 months. GHS questions do not specify a time frame, with the exception of reported visits to the GP, which is reported for the previous 12 months.

\*\*GHS does not record data on visits to STI clinics. This shows patients who reported a genito-urinary condition on their illness code.

Average costs of health care services	
A&E for serious incident (e.g. overdose) per visit	£233
In patient hospital stay per day	£282
Needle exchange per contact	£9.18
Health services cost per drug related death per person	£670
Problem drug users – total economic costs per user per annum	£35,455

Source: HO 2004

- Street workers, who have the most acute health needs, are more likely to be in contact with health care services than the general population. On average, they reported visiting the GP 8.5 times in the previous year compared to 4 times for the general population.<sup>1</sup> They also reported going to A&E 2.5 times, to an STI clinic 2.7 times, to an inpatient clinic 2 times and an outpatient clinic 4.3 times in the past 12 months.<sup>2</sup>

In spite of the fact that the majority of street workers use health services regularly, a comparatively low percentage have had routine health checks, such as cervical screening, or attend antenatal checks when pregnant.<sup>3</sup>

## Sex workers: summary of access and quality

### Sex workers experience a range of psychological and institutional barriers to accessing healthcare

Issue	Supporting evidence
<p><b>Criminalisation:</b> the criminal legal framework surrounding sex work can make sex workers wary of accessing mainstream services and of disclosing their work to health services and ‘authorities’</p>	<ul style="list-style-type: none"> <li>• Although 83% of street sex workers surveyed were registered with a GP and this was their main provider of health care, nearly two thirds (62%) had not disclosed that they were working in the sex industry<sup>1</sup></li> </ul> <p><i>“Most of the girls I met in the brothel were living a life of total secrecy ... this is rather a self destructive edge” – Gina, 29<sup>2</sup></i></p>
<p><b>Institutional factors:</b> opening hours, location and appointment systems can make accessing services difficult, particularly for those working outside of office hours. This is likely to be a significant problem for people who are alcohol or drug dependent</p>	<ul style="list-style-type: none"> <li>• Of the 80% of street workers who reported difficulties in accessing GP surgeries, the most common reasons were waiting for available appointments (52%) and difficulty keeping appointments made (51%)<sup>3</sup></li> <li>• When asked for their suggestions about effective service design, both parlour and street based workers expressed a strong preference for services located near their place of work: 79% and 90% respectively<sup>4</sup></li> <li>• Lack of access to primary care services for non-EU nationals e.g. termination pathway dependent on GP referral</li> </ul>
<p><b>Stigmatisation and discrimination:</b> fear of judgemental attitudes from health professionals or other patients can mean that sex workers do not access services or are unwilling to disclose their sex work or drug use, and may therefore not be fully able to get the right services and support</p>	<ul style="list-style-type: none"> <li>• 45% of street workers who had difficulty accessing their GP also reported fear of being judged by staff, whilst 37% were concerned that they were being ‘stared at’ by other patients<sup>5</sup></li> </ul> <p><i>“My GP is my family doctor, the one I take my children to, I would never dream of telling him what I do” – Pauline, 36<sup>6</sup></i></p>

# Promising Practice

## Model 1: Newcastle Cyrenians – Girls Are Proud (GAP project)

### Background



GAP is an innovative project providing support services to sex workers in the North East. It was established following a successful pilot project in the centre of Newcastle in 2006. The project is confidential and focuses on women's health and safety by facilitating access to drug treatment, sexual health and other statutory services. The women attending the pilot selected the name and identified the need for services specifically aimed at supporting women involved in prostitution. The project has a formal service level agreement with the Newcastle Safer Communities Partnership, working in conjunction with Drug Interventions Programme and Newcastle City Council.

Workforce: project workers and volunteers are recruited from former service users

### Service provision

GAP provides a range of services, with particular focus on accessing mainstream services:

- **Drop In:** Set up in 2006, the Gap 'Drop In' is at the heart of the project. Facilitated group sessions provide opportunities for women to discuss their experiences in an informal setting
- **Holistic Drugs Services:** A Drugs Support Worker provides direct links to treatment agencies
- **Just4Girls health clinic:** Free and confidential weekly service held in the city centre providing free condoms, smear tests, pregnancy tests, STI checks, contraception, drug treatment and someone to talk to
- **Worksafe:** Helps women who have been victim of a crime through sex work. They can receive confidential support and are given the opportunity to report crimes anonymously
- **Advocacy:** helps clients access mainstream services

### Promising practice

- ✓ **Voice:** starting as a grass-roots project, GAP raised the awareness of a previously invisible group amongst professionals – the project now has high level support within both statutory and voluntary organisations locally. The project has played a key role in brokering and advocating access to support and provision of services for its clients
- ✓ **Personalisation:** person-centred delivery is essential to maximising engagement with users. All work through GAP is peer-led. Service User involvement has been essential to the delivery of interventions and reducing the barriers to new servers engaging with the project
- ✓ **Partnerships:** current partners in the project include Government Office North East, Northumbria Police, Northumbria Probation, the local Primary Care Trust, the GUM Clinic at the General Hospital, a number of General Practitioners and Newcastle City Council

# Promising Practice

## Model 2: Matrix project, Norfolk

### Background

the **Matrix** project



The Matrix Project, established in 2004, provides a confidential, flexible and responsive outreach service to those working in the sex industry. The service aims to support both those who want to make changes to their lifestyle and those who do not, and to engage clients in harm reduction. The project works from a medical practice during the day and an outreach service at night in the red light district of Norwich and surrounding areas.

The project currently works with 40 clients and has around 500 on the database.

Workforce: four staff (manager, project worker and two support workers).

Funding: primarily funded by Norfolk PCT and Drug and Alcohol Action Team (DAAT). The service works at a minimal annual operating cost of £140k. The main provider of Matrix is Norfolk Community Health and Care.

### Service provision

The project provides an outreach service within the red light district in Norwich on variable evenings. The Matrix also works with individuals who work from home, brothels and escort agencies. Services include:

- **Streamlined one stop shop support:** sexual health screening and advice, primary health care, contraception, needle exchange etc
- **Partnership working** with medical professionals and agencies e.g. criminal justice system
- **Advocacy and referrals** to primary health care and specialist agencies
- **Advice to partners and family members**
- **Training to other professionals**
- **Area-specific research**
- **Family work**

Women self-identify via the open access services provided. Referrals come from a range of sources including GPs and drug treatment services.

### Promising practice

- ✓ **Personalisation:** clients' needs are assessed and monitored through 'models of care' forms and a care plan. Matrix takes a collaborative approach to design, receiving input from clients to ensure services are tailored to their needs. As part of the flexible service, open access day service provides drop-in centre where clients can be seen quickly
- ✓ **Partnerships:** linking up with local services and agencies to provide comprehensive health and social support
- ✓ **Outreach:** Proactive engagement via outreach service, offering a range of services at flexible times/locations to support client needs
- ✓ **Evaluation:** monthly statistics are sent to DAAT and Norfolk PCT

*"The aim was to develop a service that would really work for this client group who are historically known not to engage with services and to be very isolated in the way in which they work"*

# Promising Practice

## Model 3: Praed street

### Background



The Praed Street Project provides sexual health and support services for women from all over the world who work, have worked or are associated with any part of the sex industry. It was launched in 1985 and is based at St Mary's Hospital in Paddington, which is part of the Imperial College Healthcare NHS Trust. The project was the UK's first dedicated sexual health service for female sex workers. All services are free and confidential.

**Workforce:** five core members of staff, including a project manager, dedicated sexual health nurses and project workers

**Funding and Commissioning:** The service is mainly funded by PCTs through Payment by Results.

### Services provision

There are three main elements to the service:

- **1. Genito Urinary Medicine Clinic**
  - Daily appointments provided by consistent and specialist clinical team
  - Support of wider GUM team and close association with onsite diagnostic laboratories
  - Consultations address both sexual practice within work and personal settings

- **2. Drop in service** (3 times per week)
  - Informal setting, with opportunity to discuss range of issues including sex work and safety, sexual health, condom use, negotiating, budgeting, drug and alcohol use, legal issues, CV training, child protection and exiting the industry.
- **3. Outreach** (2 times per week)
  - Engages new clients and re-engage existing clients by going to flats, contacting via the phone, internet and newspapers ads or word of mouth.
  - Builds relationships with workers in working flats
  - Provides condoms and offer basic health promotion advice

### Promising practice

✓ **Voice:** being an NHS service and on a hospital site gives staff credibility and enables them to represent clients more effectively. They also have an extremely effective commissioner who is doing work to look at a pan-London strategy

✓ **Personalisation:** a key element of building trusting relationships with clients is the continuity of staff and 1:1 working

✓ **Partnerships:** Praed Street works with and provides referral to a range of other projects including the TB team in St Mary's, the Westminster drug project, the Caravan, Poppy Project, Salvation Army and further education services

✓ **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, providing comprehensive follow-up care (treatment, completing medication, contact tracing to minimise risk of spreading infection). There is also a patient satisfaction survey and comment box. An average of 3000 attendances per year and contact with 800 individuals. The outreach team is currently visiting 47 flats

# Homeless: demographics

## Definition

- Homelessness can describe a wide range of circumstances where people lack accommodation, from sleeping rough to overcrowded/ unsuitable accommodation
- This study focuses on the group of homeless people which local authorities do not owe a duty to secure suitable temporary accommodation as they do not fall under the priority need definition (1996 Housing Act). They will tend to either sleep rough, in hostels or high shelters, squats or on friends' floors
- Other people living in poor conditions such as those in overcrowded or unfit homes are not included in this case study because they do not suffer the same barriers to accessing mainstream healthcare and are not recognised to have health needs that are substantially different from the rest of the population

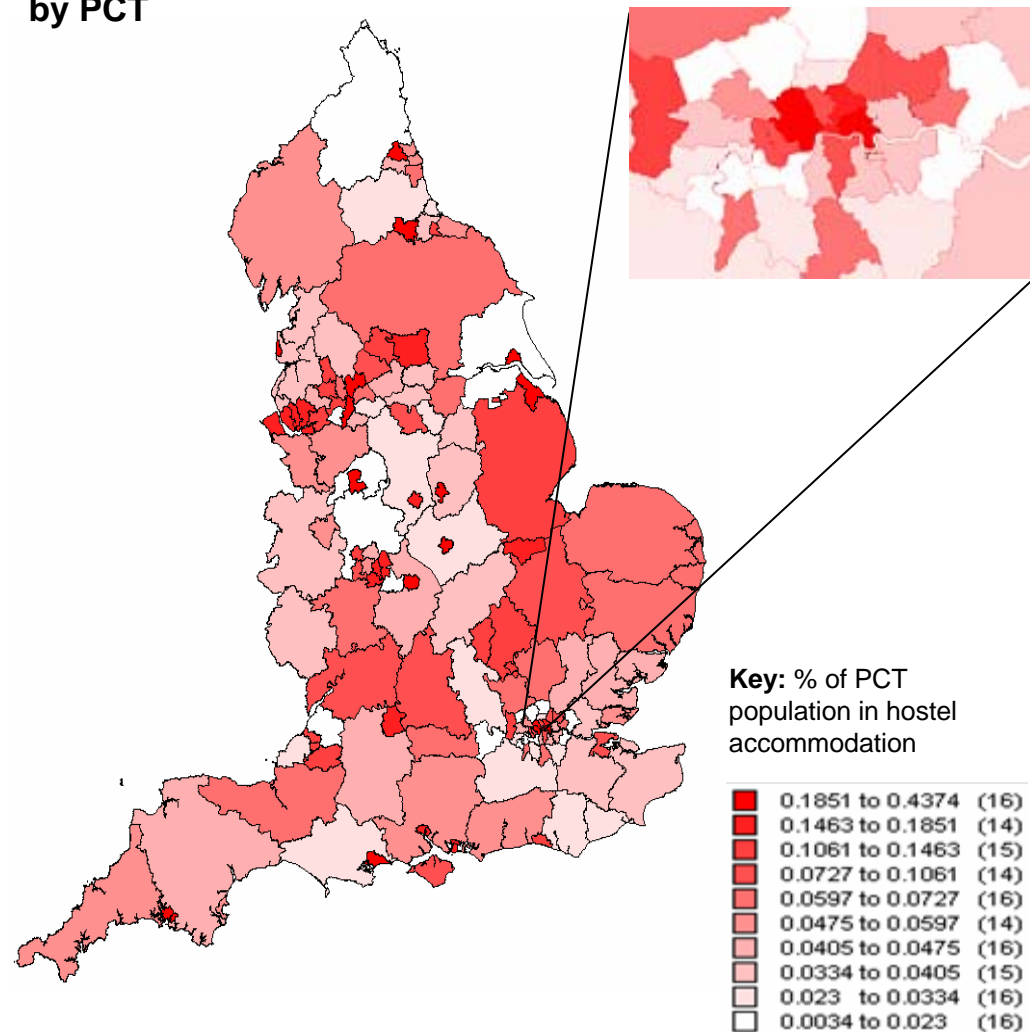
## Demographics

Population: c.40,500 at any one time; 100,000 cycle in and out of group each year<sup>1</sup>

Gender / age: c.80% of non-priority homeless are male and predominantly 20-50 years old<sup>2</sup>

Nationality / ethnicity: A study by the Broadway homeless charity found that in 2007/08 63% of homeless people in London were white, 20% black or black British, 10% from outside Europe and 5% from Central and Eastern European states (excluding Poland)<sup>3</sup>

## Number of individuals in hostel accommodation per capita by PCT



Data source: Supporting People Client Records 2007/8, mapped from LA to PCT



# Homeless: health needs and outcomes

- Homeless people have significantly higher levels of premature mortality and mental and physical ill health than the general population. As many as 40% of rough sleepers have multiple concurrent health needs relating to mental, physical health and substance misuse<sup>1</sup>
- Of those registered at Cambridge Access Surgery, a homeless specialist GP practice, 2-3% died each year between 2003-2008 and the average age of those who died was 44. Rough sleepers are 35 times more likely to commit suicide than the general population<sup>2</sup>

## Main diagnostic categories of recorded health problems among the Cambridge Access Surgery registered population (N=216)

Health problem	%	
Drug dependence syndrome	62.5	Compares to estimated 3.4% in the general population (0.9% non cannabis) <sup>3</sup>
Mental ill-health	53.7	
Alcohol dependence syndrome	49.1	Compares to estimated 5.9% in the general population (0.5% moderate to severe) <sup>4</sup>
Dual diagnosis*	42.6	
Injuries/Assault	26.4	
Hepatitis C Virus antibody positive	17.6	Compares to estimated <0.5% in the general population. <sup>5</sup>
Respiratory diseases	16.7	
Liver disorders/ abnormalities	15.7	
Other infections (sepsis, abscesses, MRSA, C-difficile)	13.9	
Other health problems**	31.5	

\*Mental health and substance misuse problems.

\*\*Dental problems, gastroenterological diseases, deep venous thrombosis (DVT), skin conditions, epilepsy/ fits, urogenital diseases, learning/ physical disability, anaemia, cardiovascular diseases and cancer.

Findings from the Cambridge study are supported by a substantial body of evidence on the acute health needs of homeless people:

Health risks	Supporting evidence
Physical health	<ul style="list-style-type: none"> <li>▪ Rough sleepers have a rate of physical health problems two or three times higher than the general population<sup>6</sup></li> <li>▪ 47% have at least one physical health need at a given point in time; 27% have concurrent multiple physical health needs; a third have conditions for which no treatment has been received<sup>7</sup></li> </ul>
Mental health	<ul style="list-style-type: none"> <li>▪ 50-75% of rough sleepers have Axis I disorder (anxiety disorders, depression, dementia and psychosis disorders), and as many as 30% have schizophrenia<sup>8</sup>. 58% have Axis II personality disorder ('complex trauma')<sup>9</sup></li> </ul>
Substance misuse	<ul style="list-style-type: none"> <li>▪ 60-90% of rough sleepers are regular drug users<sup>10</sup></li> <li>▪ 50% of rough sleepers are alcohol reliant<sup>11</sup></li> </ul>
Skin Problems	<ul style="list-style-type: none"> <li>▪ Infestations: body, pubic/head lice, scabies. Infections including MRSA, fungal dermatitis, psoriasis</li> </ul>
Respiratory problems	<ul style="list-style-type: none"> <li>▪ Chronic chest / breathing problems and frequent headaches are 3 times higher than general population<sup>12</sup></li> </ul>
Trauma	<ul style="list-style-type: none"> <li>▪ Foot trauma related to poor hygiene, walking in poor footwear. All accidental and inflicted trauma, with increased complications (owing to high incidence of assault, intoxication, self neglect)</li> </ul>
Dental	<ul style="list-style-type: none"> <li>▪ Dental caries frequently needing dental clearance</li> </ul>
Tuberculosis	<ul style="list-style-type: none"> <li>▪ Rates of TB 200 times that of known rate in general population<sup>13</sup></li> </ul>

## Homeless: acute care usage

### Findings from OCA study<sup>1</sup> of No Fixed Abode patients in Hospital Episode Statistics showed that:

- 86% of all no fixed abode (NFA) episodes were admitted as emergencies compared to only 42% for inpatients with a fixed place of residence. Over 30% of NFA episodes are for the A&E speciality compared to less than 3% for the general population.
- 8% of NFA episodes are for the mental health speciality compared to 1% for the general population.
- Owing to the severity of their health conditions, homeless people (NFA) have an average length of stay more than double the non-homeless population.

St Mungo's have also found that **the majority of ambulances called for their clients were for pre-existing conditions which had reached the point of urgent attention**, and 21% of clients required multiple ambulance call-outs<sup>2</sup>

Figures from Newcastle PCT show that a group of 60 people who experience a mixture of substance dependence, mental health issues and sometimes homelessness, had over 1,000 admissions to A&E in the course of a year<sup>3</sup>

### Top reasons for admission for the no fixed abode and fixed abode population

No Fixed Abode		Fixed Abode	
Reason for admission	% of all episodes	Reason for admission	% of all episodes
Poisoning, Toxic, Environmental and Unspecified Effects	7.97%	Antenatal Admissions not Related to Delivery Event	4.91%
Examination, Follow up and Special Screening	5.79%	Diagnostic Procedures, Oesophagus and Stomach	2.76%
Alcohol or Drugs Dependency	5.69%	Normal Delivery w/o cc	2.53%
Alcohol or Drugs Non-Dependent Use >18	4.28%	Large Intestine – Endoscopic or Intermediate Procedures	2.52%
Schizophreniform Psychoses w/o Section	2.90%	Intermediate Mouth or Throat Procedures	1.98%
Sprains, Strains, or Minor Open Wounds <70 w/o cc	2.86%	Phakoemulsification Cataract Extraction and Insertion of Lens	1.95%
Epilepsy <70 w/o cc	2.46%	Neonates with one Minor Diagnosis	1.83%
Chest Pain <70 w/o cc	2.29%	Bladder Minor Endoscopic Procedure w/o cc	1.48%
Acute Reactions or Personality Disorders	2.27%	Planned Procedures Not Carried Out	1.28%
Head Injury <70 w/o cc	1.75%	Minor Skin Procedures – Category 1 w/o cc	1.28%

Source: *Healthcare for Single Homeless People* (Office of the Chief Analyst, Department of Health, 2010)

Outpatient  
£4.4 million

**£85.6 Million**

Total estimated annual secondary care costs for 40,500 homeless people

5 times more per person than the average

Inpatient  
£76.2 million

8 times more per person than the average within 16-64 age range

A&E  
£5 million

Not including ambulance journeys

## Homeless: wider needs

### Centrepoint: data collection on health needs<sup>1</sup>

Data on health needs of clients is collected upon first access to Centrepoint. These assessments reveal the following health needs\*:

- 13% report physical health problems
- 6% report anxiety disorders
- 11% report mental health conditions
- 14% report depressive disorders
- 10% problematic drug/alcohol use

\*This data can often underestimate the full scope of health needs as clients are often reluctant to disclose personal information until a relationship of trust is built.

### St Mungo's LifeWorks Project<sup>2</sup>

Established in 2008 and funded by the Adults Facing Chronic Exclusion (ACE) programme, the LifeWorks project provides counselling services to excluded adults who are either homeless, or at risk of being homeless.

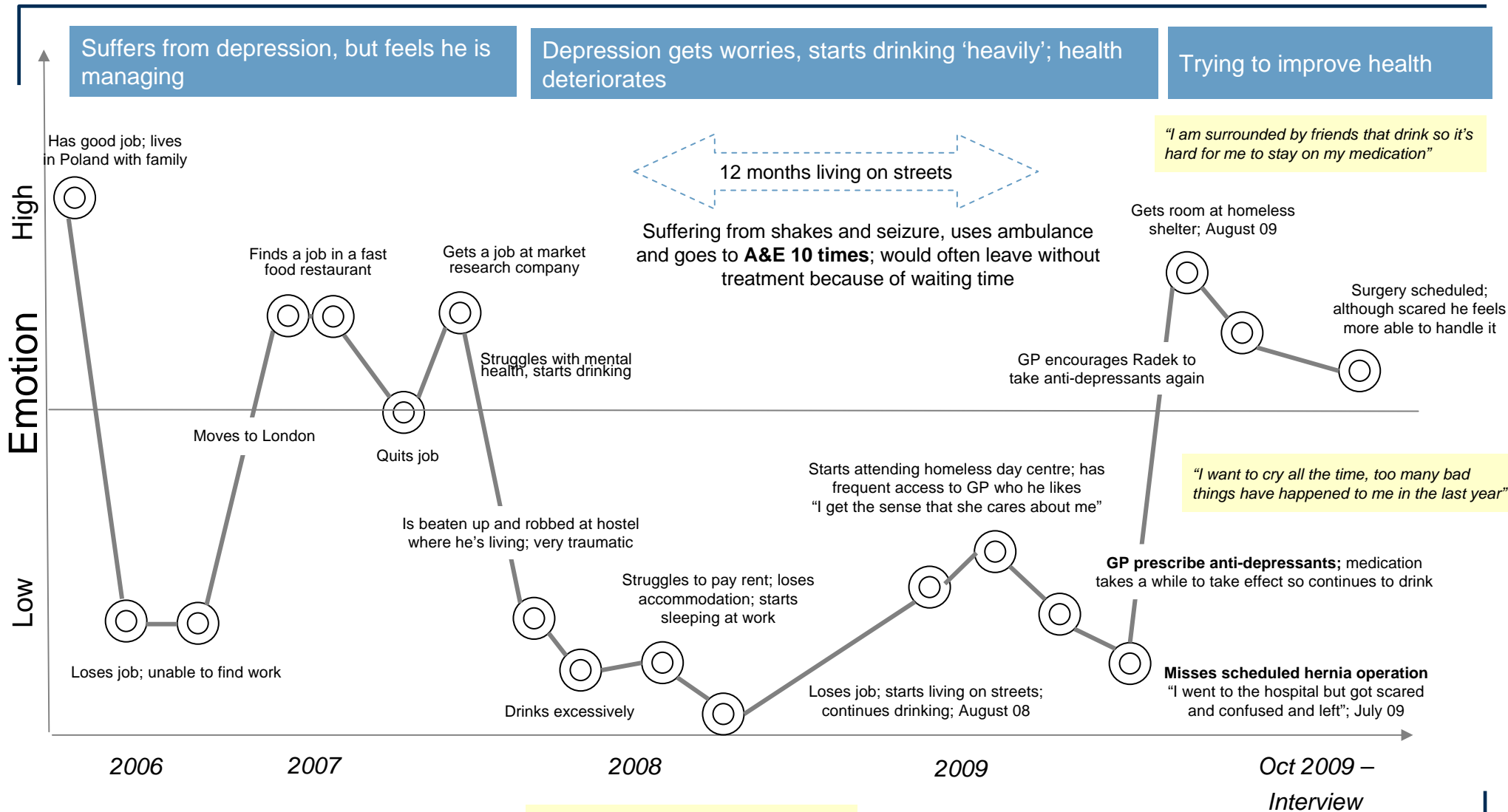
The service was set up in response to meet the complex and often multiple needs of homeless clients who can often be excluded from mental health services due to substance misuse – 43% of St Mungo's LifeWorks clients have substance misuse issues, a history of social exclusion and mental health problems. It offers up to six months of weekly psychotherapy sessions to users, who either self-refer or are referred by social workers.

Since inception, the project has worked with approximately 166 clients, with 75% positive outcomes on the Wellbeing Impact Assessment Measure. Costs are estimated at £1,500 per client, the equivalent of three weeks staying in a hostel.

Social determinants	Supporting evidence
Income and employment	<ul style="list-style-type: none"> <li>• Homeless people face multiple barriers to employment, particularly those with drug or alcohol problems and an offending history. Homeless people are characterised by low levels of basic skills, language problems and negative employer perceptions</li> <li>• There are no specific national employment targets for people who are homeless and few services focus explicitly on helping homeless people into work</li> </ul>
Education and skills	<ul style="list-style-type: none"> <li>• Research found that more than half of people want to engage in learning, but that less than a fifth do so.<sup>3</sup></li> </ul>
Housing	<ul style="list-style-type: none"> <li>• Ill health is both a factor that can cause homelessness and is also often a result of homelessness.</li> <li>• One London-based study found that people become less likely to move to long-term accommodation after two to two and a half years in one hostel. Younger rough sleepers were more likely to abandon bed spaces, whereas the proportion of rough sleepers who left accommodation as part of a planned move increased in line with age.<sup>4</sup></li> </ul>
Immigration	<ul style="list-style-type: none"> <li>• Centrepoint, a national homeless charity, reported that over a quarter (27%) of their clients are refugees, many of whom have suffered torture, exploitation or acts of war which have left them with post-traumatic stress or severe depression</li> <li>• A Canadian study found that new immigrants are more likely to cite economic and housing factors as barriers that keep them homeless compared with native-born individuals, rather than health factors<sup>5</sup></li> </ul>
Lifestyle behaviours	<ul style="list-style-type: none"> <li>• Along with drug, alcohol and mental health problems, leaving prison was one of the top factors contributing to homelessness among 257 rough sleepers interviewed by Shelter in 2007.</li> </ul>

# Case study

Radek – late 20s – had mental health conditions leading to excessive drinking and homelessness



## Homeless: summary of access and quality

Issue	Supporting evidence
<p><b>Institutional factors:</b> Barriers to GP registration (such as requirement of proof of address), opening hours, inflexible appointment systems</p>	<ul style="list-style-type: none"> <li>• Homeless people are 40 times more likely to be unregistered with a GP and are five times more likely to use A&amp;E when they could not speak to a doctor than the general public. 81% of GPs interviewed by Crisis thought that it was more difficult for a homeless person to register than the average person<sup>1</sup></li> <li>• Literacy problems are a huge and under-reported problem and telephone services (e.g. NHS direct) are expensive to call from a mobile and can be complex or hard to follow<sup>2</sup></li> <li>• Homeless people generally have poor engagement skills and dysfunctional lifestyles which makes it unlikely for them to book and keep appointments<sup>3</sup>, which also make it difficult to successfully refer patients<sup>4</sup></li> <li>• GP opening times can be a barrier<sup>5</sup> and Crisis clients have reported trouble finding out what is available to them and where the services are based<sup>6</sup></li> <li>• There are financial disincentives for GPs to register rough sleepers<sup>7</sup>. A rapid turnover of patients with complex health needs makes QOF targets more difficult to achieve<sup>8</sup></li> </ul> <p><i>“When you seek help ... they ask you all these questions, questions I can't answer, like who was your previous doctor ... what is the address ... I don't know, I just want help ... when you are trying to get your life back on track, you want help immediately ... because there might not be another chance” – Lee, 32 (SETF, 2009)</i></p> <p><i>“I have probably missed more psychotherapy appointments than I have gone to ... I struggle to go most of the time ... I think this is because of my condition” – Justin, 21 (SETF 2009)</i></p>
<p><b>Stigmatisation and discrimination</b></p>	<ul style="list-style-type: none"> <li>• A QNI survey of prospective professional members of Homeless Health Initiative (HHI), made up of nurses, midwives and health visitors, identified stigmatisation of homeless people by mainstream health professionals as the most significant barrier to providing appropriate healthcare to homeless people<sup>9</sup></li> </ul> <p><i>“I was homeless and he didn't want me around. He [the GP] perceived me as to be a problem...I mean, he's a lot better now I've got a stable address and all that, he treats me with respect”<sup>10</sup></i></p>

## Homeless: summary of access and quality

Issue	Supporting evidence
<p><b>Service provision:</b> Paucity of specialist services; often services unable to deal with complexity of health problems; inadequate referral and discharge</p>	<ul style="list-style-type: none"> <li>• Of 125 primary care trusts provided to homeless people across England, 48 were found to have no specialist provision for homeless people. Although this may be attributable to the fact that some PCTs have small homeless populations, it is likely that there are others where a specialist service is justifiable but not currently funded<sup>1</sup></li> <li>• Mental health services will often not work with people who have drug or alcohol problems<sup>2</sup> – and there is often a lack of access to psychological therapies for people with complex problems<sup>3</sup></li> <li>• Follow up and referrals to secondary care can be poor and undermine a clients' longer term recovery or treatment. It is important that housing needs are incorporated into this care<sup>4</sup> although short term admissions make it difficult to link people into appropriate support / housing in the time available<sup>5</sup></li> <li>• There is variation between hospitals' policies in discharging people without anywhere to go.<sup>6</sup> A case study in Newcastle highlights that while hospital staff had a holistic perspective on working with elderly people, the attitude for complex homelessness cases had previously been: <i>"They walked in here - why can't they walk out"</i><sup>7</sup></li> </ul>
<p><b>Lifestyle and behaviour</b></p>	<ul style="list-style-type: none"> <li>• Some homeless people will not seek assistance until their health is critical, as health needs are often surpassed by other more immediate priorities</li> <li>• High levels of mobility often result in lack of continuity of care and difficulty in ensuring that test results get to clients – HHI have heard of at least on instance where this has lead to a patient's death<sup>8</sup></li> </ul>
<p><b>Workforce:</b> Lack of staff training and user engagement</p>	<ul style="list-style-type: none"> <li>• Only 36% of the 105 members of the HHI surveyed had received any training on health homelessness issues<sup>9</sup></li> <li>• Although most HHI members wanted to involve service users, only half (49.5%) did at the time of the survey<sup>10</sup></li> </ul>

*"I was on a destructive streak; I did a lot of bad things to myself and didn't know how to deal with it... I was kinda going to all these doctors, trying to look for help, looking for some sort of release and to retrieve myself back ... but I'm kinda disillusioned with the health care you know"* – Martin, 22 (SETF, 2009)

# Promising Practice

## Model 1: Mobile X-Ray Unit

### Background



Based on a unit that operated in Rotterdam, the Mobile X-ray Unit (MXU) provides a mobile tuberculosis screening service from a van that visits London homeless hostels, as well as prisons.

Over the course of 21 months, more than 20,000 individuals had chest x-rays, with very high rates of undetected TB (per 100,000 screened) found among problem drug users (717), homeless people (338) and prisoners (200).

The project is staffed by a social worker, nurses (one prison based) and an outreach worker and receives its funding from the Department of Health. There is often a challenge in making the case to London PCTs to fund a service for a small and dispersed population

### Service provision

The MXU van aims to address the high prevalence of TB in London amongst homeless people, raise awareness of the and promote the importance of screening over the long-term.

- **Drop In:** The MXU visits London hostels twice a year on a rolling 6 month programme, working closely with hostels to try to ensure that all residents are screened
- **Rapid detection:** Staff are able to X-ray and identify possible TB infections within a few minutes
- **Supported referral:** Where a potential case of TB is identified, it is explained to clients and, ideally, they are taken directly to one of London's 30 specialist TB clinics. As an x-ray and sputum sample will already have been taken, client referral and treatment time can reduce from two weeks to within one-two days

### Promising practice

- ✓ **Personalisation:** A peer advisory group ensures service user involvement
- ✓ **Outreach:** Health is often not a priority for the homeless. This 'find and treat' outreach model is responsive to their needs, seeing clients immediately and enabling faster referrals in the case of TB detection
- ✓ **Evaluation:** It is estimated that the intervention prevented 11 cases of active tuberculosis in the first year with projected estimates of cases prevented increasing to about 87 cases per year by 2013. MXU saves £1,912 per case prevented (given certain assumptions).

Uptake among homeless people is predominantly determined by the ability of skilled workers to inform and motivate residents and by the timing of the intervention – HPA evaluation, 2007.

# Promising Practice

## Model 2: Homeless intermediate care pilot – Cedar’s Road hostel

### Background



Based in St Mungo's Cedar's Road hostel, the Intermediate Care pilot provides intensive support to particularly at risk clients who meet a set of referral criteria:

- Resident of Cedar's Hostel at time of being accepted on to the project
- Registered or consenting to register with the Courtyard Surgery
- Not independently meeting their own health needs
- Has a deteriorating medical condition which will benefit from intensive nursing intervention
- At imminent risk of unplanned hospital admission
- Is judged to be at most imminent risk of death / increasing disability by the intermediate care team
- Willing to engage, and consents to take part in research data collection

The project team consists of three members of staff – care doctor (working 4.5hrs a week), a nurse and support worker

### Service provision

The aim of the pilot is to reduce the mortality and morbidity in clients residing at the hostel, in tandem with reducing their secondary care usage. The service offers intensive support to up to 10 clients over a 6-12 week period.

- **Outreach:** Building trusted relationships with clients
- **Clinical interventions:** Administering medication, taking blood tests, wound dressing, personal care etc
- **Liaison and referrals:** Helping clients to engage/reengage with all of the specialist services that they should be accessing
- **Screening and prevention:** Carrying out Comprehensive Health Assessments, cervical and sexual health screening, blood screening, vaccinations etc
- **Advocacy:** Escorting clients for appointments/visits
- **Research data collection**

### Promising practice

- ✓ **Advocacy:** The support of dedicated staff ensures that clients are accessing the services they need
- ✓ **Personalisation:** Services are tailored to the (often multiple) needs of the homeless clients by means of intensive, time-limited interventions to improve health outcomes
- ✓ **Recovery:** The service goes beyond immediate treatment to promote healthy, long-term lifestyle choices
- ✓ **Evaluation:** In 2009, 33 clients benefited from the project. Of those, the prevalence of illness was extremely high (18% were diagnosed with HIV, 32% had a past case of Hep B, 72% had active or past Hep C, 87.5% had been intravenous drug users, 73% were alcohol dependent, 82% had mental health problems). In 2008, there were 7 deaths at Cedars, and the average age of death was 38 years old. During 2009, there was only one death, with the lower rate being attributed to the intermediary care project.

*"...people here find it hard to go to people to talk about their health. We need coaxing... because we are all messed up" – Cedars Road hostel client*



# Promising Practice

## Model 3: Safe Haven Practice

### Background



Safe Haven practice, based in King's Cross and funded by Camden PCT, is part of a multi-disciplinary team providing primary health care to homeless people and those with substance misuse issues in Camden. The Safe Haven Project was established in April 2006 by Camidoc, Camden and Islington PCTs to accommodate patients removed from GP lists owing to their unacceptable behaviour.

The Safe Haven practice operates under a client contract, which includes client commitments to

- Pre-book routine appointments, and not to approach other practices for appointments
- Accept that there may be delays in getting seen, understanding that immediate appointments may not be possible for a non-urgent reason
- Conduct themselves in a way that does not cause disruption whilst waiting for / during appointments
- Understand that causing a disturbance or threatening staff will result in a breach of contract and may result in them being removed from the Safe Haven list.

### Service provision

Clients are initially referred from the PCT and have all previously been removed from their GP's list. They are invited to an initial appointment and undergo a full health assessment. No fixed abode patients are able to register the practice as their address. The practice is staffed by a GP, Safe Haven coordinator and security guard.

- **Flexible appointments:** Walk-in sessions twice a week or fixed appointments available (longer time), dedicated out of hours service and dentist on site
- **Screening and prevention:** Hepatitis and HIV screening, vaccinations, cervical screening, free contraception
- **Liaison and referral:** Referral for counselling, substance misuse services, mental health services
- **Clinical interventions:** Chronic disease management, general health care, blood tests etc

### Promising practice

- ✓ **Partnerships:** For example, linking up with University College Hospital London to provide assistance to homeless patients, benefits and housing advice, information on dentistry and podiatry treatments
- ✓ **Personalisation:** Availability of longer appointments, out of hour service etc. The practice enables clients, who otherwise would not have access, to engage with primary healthcare services whilst being clear that clients also have to fulfil their responsibilities as registered users of the practice.
- ✓ **Recovery:** Providing holistic services that meet breadth of client need rather than just presenting illness, working to promote longer-term healthier lifestyles.
- ✓ **Trusted relationships:** Building rapport with clients and encouraging them to re-engage with health services in a less chaotic way. The project has seen a reduction in A&E attendances and client self-referral to secondary healthcare services.

# Gypsies and Travellers: demographics

## Definition

- While there is no accepted definition, in the context of this study, Gypsies and Travellers are taken to mean all persons with a cultural tradition of nomadism or of living in a caravan and all other persons of a nomadic lifestyle, whatever their race or origin
- Some of these communities live nomadically while others live on authorised sites or in housing.
- Romany Gypsies and Irish Travellers are recognised as ethnic groupings under the Race Relations Act 1976 (Matthews, 2009).

## Demographics

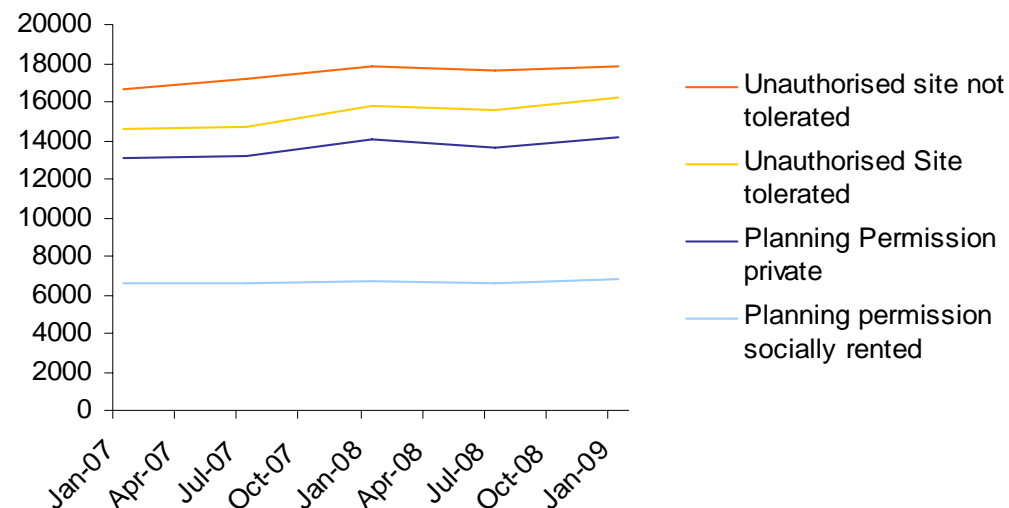
### Population:

- Although Gypsy and Traveller communities are poorly captured in most national datasets, Communities and Local Government estimates they represent 0.6% (c.368,000) of the total UK population.
- The Council of Europe and the Gypsy Council have estimated that the population living in permanent housing is 200,000.

### Nationality and ethnicity:

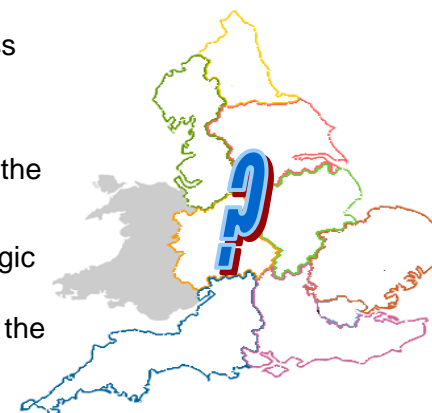
- A diverse number of communities have been recognised, including Romany Gypsies (who settled in the UK over 500 years ago), Roma (more recent arrivals from Eastern Europe), Scottish Travellers, Welsh Travellers (Kale), Irish Travellers, New Travellers, Bargees, Showpeople and Circus People
- Estimates suggest that the largest group in England, possibly half of all the community, is Romany Gypsies (63,000), followed by Irish travellers (19,000).<sup>1</sup>

## Local Authority bi-annual caravan counts provide the only source of demographic data at a national level



## Although hard to track, research shows that Gypsies and Travellers move across the country

- Gypsies and Irish Travellers live in or pass through 91% of local authority areas in England and Wales<sup>2</sup>
- 13% of local authorities suggest they are the largest ethnic minority group in their area<sup>3</sup>
- However, fewer than half of PCTs, Strategic Health Authorities and Primary Health Organisations report holding knowledge of the numbers and location of travellers and Gypsies in their locality<sup>4</sup>



# Gypsies and Travellers: health needs and outcomes

Official statistical data are not collected on the health needs of Gypsies and Travellers, but research suggests poor outcomes

Health condition	Example of evidence
<b>Mental health</b>	Gypsies and Travellers are nearly three times more likely to be anxious than average and just over twice as likely to be depressed. Women are twice as likely to experience mental health problems than men <sup>1</sup>
<b>Diabetes</b>	A High prevalence of diabetes has been reported and a lack of community knowledge of the risk factors <sup>2</sup>
<b>Respiratory problems</b>	22% and 34% Gypsies and Travellers reported having asthma or chest pain compared to 5% and 22% of age and sex comparators. Three times more likely to have chronic cough or bronchitis even after smoking status taken in to account. <sup>3</sup>
<b>Maternal and infant health</b>	Excess prevalence of miscarriages; stillbirths, neonatal deaths. High rates of maternal death during pregnancy and shortly after childbirth have been reported (Pet al, 2004); the majority of deaths considered preventable <sup>4</sup>
<b>Long term illness</b>	38% of G&T have a long term illness compared with age and sex matched comparators even after controlling for socio-economic status and other marginalised groups. <sup>5</sup>

## Life expectancy

A study of Irish Travellers in Ireland reported that the women live 12 years less than women in the general population and Gypsy and Traveller men 10 years less.

90% of individuals in current life expectancy statistics live to age 60 or beyond.

Some GTAA's report between 10-13% of English Travellers are aged over 60 while evidence suggests that just 30% of Irish Travellers live beyond 60.

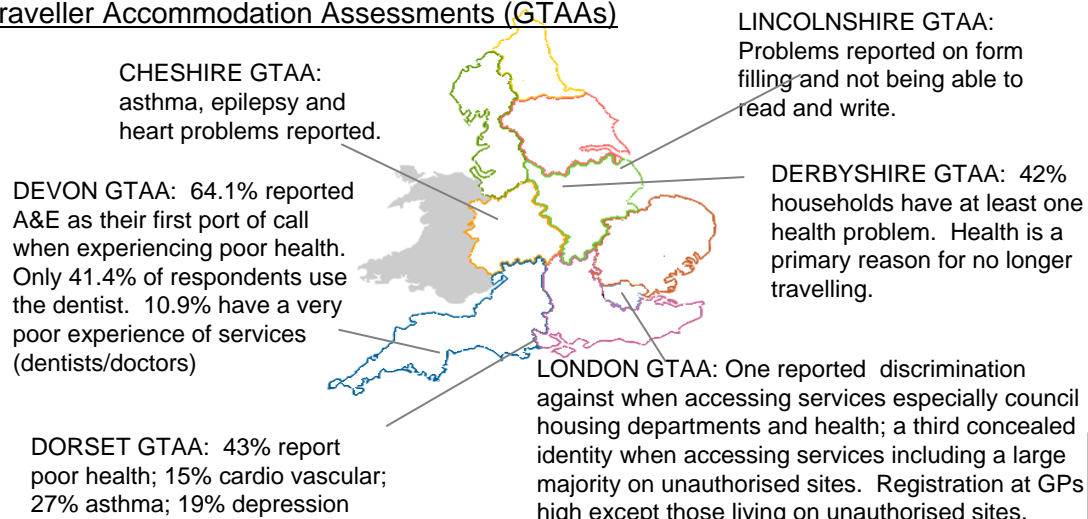
## Teeth

Access to dental care and oral health reported but little evidence exists. There is some suggestion from GTAA's and casework that access is worsening.<sup>9</sup>

## Prescription drugs

Case studies reveal examples of repeat prescriptions being renewed without review for long periods, particularly when families are highly mobile, and also inappropriate usage (wrong dosage, frequency or sharing prescriptions) due to literacy problems.<sup>8</sup>

## Snapshot of key issues reported through local Gypsy and Traveller Accommodation Assessments (GTAAs)

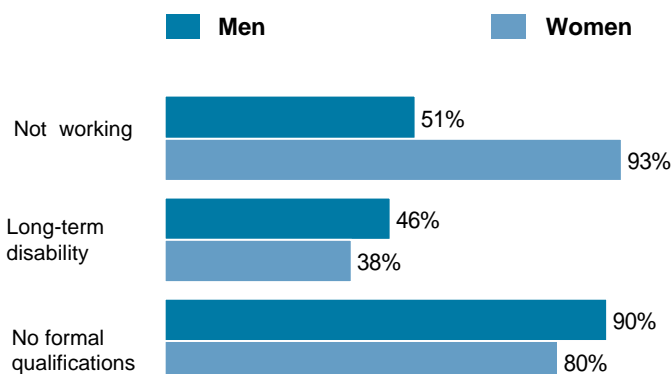


Health care staff commonly report that patients commonly present with more than one condition.<sup>6</sup>

Three in ten Gypsies and Travellers say their health is either bad or very bad. Just one in twenty of the wider regional population say the same.<sup>7</sup>

## Gypsies and Travellers: wider needs

Proportion of Gypsies and Travellers out of work, with a long-term disability and with no formal qualifications in East England Strategic Health Authority:



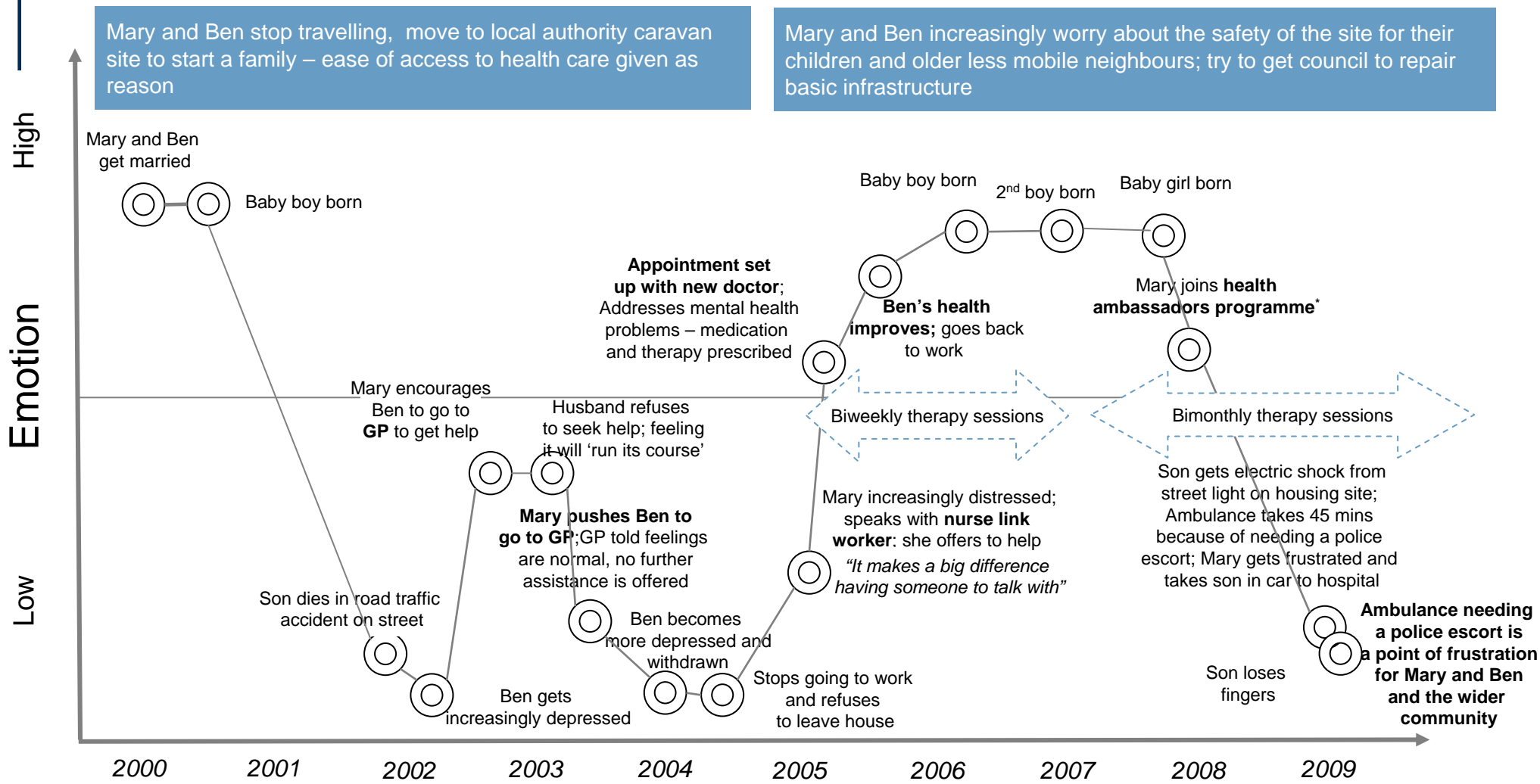
Poor site conditions can have a major impact on health outcomes



Social determinant of health	Example of evidence
Income/ Employment	<ul style="list-style-type: none"> <li>• Lack of systematic data, but evidence reveals strong preference for male self employment e.g. in gardening, scrapping metal, building and market trading<sup>1</sup></li> <li>• High percentage of women do not work outside the home</li> <li>• Frequent evictions and being moved on reduce ability to access sustained employment</li> </ul>
Education and skills	<ul style="list-style-type: none"> <li>• Despite some progress, Gypsy and Traveller children remain highly disadvantaged in terms of access, inclusion and achievement, the vast majority lingering on the fringes of the system</li> <li>• The average school attendance rate for all Traveller pupils is around 75% (well below the national average), while there is a marked decline between access and attendance at primary level (2820 Travellers of Irish Heritage and 6340 Gypsy/Romany registered January 2009) and secondary level (1040/ 3070 registered Jan 2009). Ofsted estimated 12,000 Gypsy, Roma and Traveller children might not be registered at secondary school<sup>2</sup></li> <li>• Attainment is also well below average: in 2007 only 16% of Irish Travellers and 14% of Gypsy/Roma achieved 5+ A*-C GCSEs or GNVQs compared to 59% of all pupils</li> </ul>
Accommodation and site conditions	<ul style="list-style-type: none"> <li>• A review of 152 local authorities with unauthorised encampments showed that 8 had not produced a homelessness strategy, and 72% of those that had did not refer to Gypsies and Travellers</li> <li>• Poor site conditions 14%-30% of Travellers have no or limited access to clean water, while 33%-58% have no access to water or chemical toilets.<sup>3</sup></li> <li>• Existing public sites are often at a distance from public services and near to motorways or major roads (26%); rubbish tips (12%); industrial or commercial activity (8%) and sewage works (3%).<sup>4</sup></li> <li>• An undetermined number of Gypsies and Travellers are averse to conventional housing</li> </ul>
Lifestyle behaviours	<ul style="list-style-type: none"> <li>• An Ipsos MORI poll found that that 47% of Gypsies and Travellers smoke compared to 18% of the general population</li> <li>• Until recently, use of illicit drugs was virtually unknown in Gypsy and Traveller communities but is becoming more common especially on estates where unemployment and alcohol misuse are common.<sup>5</sup> Practitioners note Gypsies, Irish and Scottish Travellers increased recreational drug use and heroin and crack cocaine use. Drugscope links disrupted educational experience with limited knowledge of problem drug use.<sup>6</sup> Alcoholism always known within a minority of Gypsy and Traveller populations.</li> </ul>

# Case study

## Mary and Ben – late 20s – with three children under five, experienced mental health problems but refused to seek help



\*Teaches Gypsy and Travellers communities about the health service and professionals about Gypsy and Traveller culture

## Gypsies and Travellers: summary of access and quality

ISSUE	Example of evidence
Cultural expectations	<ul style="list-style-type: none"> <li>• Van Cleemput et al (2007) report Gypsies and Travellers' sense of fatalism with regard to treatable health conditions and low expectations of enjoying good health - especially as they age "<i>ill health is seen as normal, an inevitable consequence of adverse social experiences</i>".<sup>1</sup> Anecdotally, male Gypsies and Travellers are traditionally reluctant to engage with or talk about matters of health.<sup>2</sup></li> <li>• It is also reported that there is a perception that unless you are 'examined' you are not getting correct medical treatment<sup>3</sup></li> </ul>
Site conditions/ local context	<ul style="list-style-type: none"> <li>• Lack of information or the conditions of sites can lead to the services being reluctant to enter e.g. residents on a site in Leicester reported that ambulances would wait for a police escort before responding to 999 calls.<sup>4</sup></li> <li>• Privacy issues are important within the community. Outreach can be inappropriate if examinations are being done in thin walled trailers or caravans<sup>5</sup></li> <li>• Isolation of some Gypsy and Traveller sites can create problems in accessing dentists and opticians. Gypsies and Travellers report feeling 'forced' into housing as a result of personal (often health-related) circumstances and external pressures.<sup>6</sup> Supporting this, WHO found that those who rarely travelled had a worse health status.</li> </ul>
Registration	<ul style="list-style-type: none"> <li>• One of the most commonly reported problems for Travellers accessing GPs is insistence on having a permanent address.<sup>7</sup> Some GPs only register families as temporary residents<sup>8</sup></li> <li>• Poor literacy and, for recently migrant Roma communities, English can make it very difficult to navigate the health system.<sup>9</sup></li> <li>• Having previously had poor experiences or heard about them from friends and relatives, many Gypsies and Travellers anticipate discrimination from GP practices or at A&amp;E (Sussex site visit, SETF fieldwork. As a result some Gypsies and Travellers, particularly those living in bricks and mortar accommodation, will not identify their ethnicity<sup>10</sup></li> </ul>
Health professionals knowledge/training	<ul style="list-style-type: none"> <li>• Health professionals can lack knowledge/confidence/expertise about the beliefs and culture of Gypsy and Traveller communities. Without understanding from either professionals or clients 'hackles can be raised'.<sup>11</sup></li> </ul>
Transience	<ul style="list-style-type: none"> <li>• Those who are mobile have an increased reliance on A&amp;E and walk in centres which can lead to problems with follow up and continuity of care.<sup>12</sup></li> <li>• Gypsies and Travellers are known to travel long distances to see GPs that they trust<sup>13</sup></li> </ul>

# Promising Practice

## Model 1: Family, Friends and Travellers (FFT), Sussex

### Background



Based in Sussex, FFT is a national charity working solely on Gypsy and Traveller issues. In 2003, FFT set up their health project to address some of the health related issues being experienced by the Gypsy and Traveller community in Sussex. This has developed into a new approach towards helping travelling families overcome barriers in accessing health and social care.

Funding: the health project was originally funded for three years (2003-06) by DH and Volunteering England. Funding for the work that FFT continues to take forward is fragmented: the organisation receives 15 different funding streams from a range of charitable bodies, Government Departments and pockets of local money that all need to be reported on separately.

### Service provision

FFT aims to take a holistic approach to health which includes key social and behavioural determinants as well as those relating to disease and biomedicine. Its service includes:

➤ **Outreach:** Core to FFT's work is outreach and engaging with individuals and families who are largely invisible to services and supporting them to access these services. FFT have six outreach workers with different remits including mental health and adult social care. Building on the trusting relationships FFT has built with the local community, FFT acts as an intermediary to statutory services who do not provide outreach

➤ **Health Project Voluntary Group:** Informal group which identifies health needs through sessions on other activities such as traditional craft and cooking. In response to these themes, training sessions for the local Gypsy and Traveller Community were held in a diverse range of issues including quitting smoking, pregnancy and menopause, basic skills and health entitlements

### Promising practice

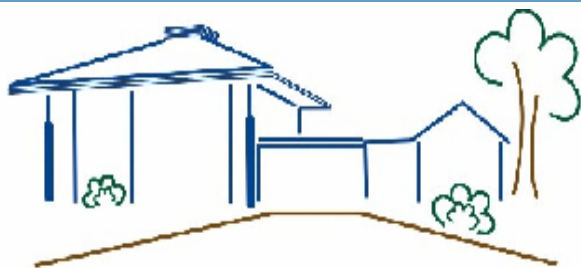
- ✓ **Focus:** Long term engagement has established a relationship of trust with the local community of Gypsies and Travellers
- ✓ **Voice:** FFT understand the needs and lifestyles of Gypsies and Travellers and are well placed to offer appropriate advice and information about services
- ✓ **Professional development and partnership:** FFT run cultural capability and training for service providers and practitioners helping to raise awareness about the community's needs and professionals adapt services to be culturally sensitive

Previously, it was reported that no Gypsies and Travellers were accessing social care services locally. Over 180 outreach visits by the team have led to 90 referrals to social care, with 50 of these subsequently requiring services e.g. an Occupational Therapy assessment led to handrails being fitted on a trailer. Outreach workers have taken over 80 people to a local NHS dentist that also has experience with homeless clients.

# Promising Practice

## Model 2: Market Harborough Medical Clinic

### Background



In Market Harborough, one GP practice has set up an enhanced service to meet the health needs of Travellers in the local area (there are two large sites and one small site in the catchment).

Previously, the practice had often experienced problems treating Travellers owing to their lack of understanding about the systems for accessing healthcare, inadequate past medical records and fear or prejudice amongst some staff members.

Building on the expertise of the long-standing specialist health visitor service in Leicester, the practice was able to enhance its understanding of the issues facing Travellers and address the fact that the surgery's fairly rigid processes were contributing to access problems. Rather than attempting to change the behaviour of Travellers, the practice sought to change its own service.

Cost: c.£100 per Traveller; c.£50,000 total per year

### Service provision

The practice applied to the PCT for a local enhanced service to help recoup the estimated financial costs of offering an inclusive service for Travellers including:

- **Registration:** Registering as many as possible and not deregistering those away for over 6 months
- **No turn away:** No clients to be turned away without consultation or an agreed appointment
- **Family consultations:** Requests accepted to see family members in the consulting room
- **Read Code:** Coded thesaurus of clinical terms applied to all identified Travellers
- **Template record** used to collect health needs of Travellers
- **Outreach:** Practice nurse appointed and trained to visit Traveller sites twice a week; male doctors prepared to visit sites to encourage older men to attend surgery for screening and diagnosis
- **Travel forums** held to monitor users views of the services provided

### Promising practice

✓ **Focus:** The clinic focuses on the health needs and outcomes of the local Traveller community

✓ **Personalisation:** Efforts to understand the cultural values and customs of Travellers with the resident local Traveller population has won trust over time and taken 'heat' out of interactions with GP practice staff. Through innovative design the clinic has managed to adapt and tailor its own service to meet the needs and challenges of the Traveller community

✓ **Additional funding** from the PCT Enhanced Service covers any loss the practice would encounter from the Quality Outcomes Framework

It is reported that:

- Registration has increased to about half the Traveller population
- Stress among reception staff has decreased considerably, since they no longer have to refuse any Traveller asking for a consultation
- The service has led to a notable increase in trust amongst the Traveller community



# Promising Practice

## Model 3: Pacesetter innovations Newham

### Background



NHS Newham Pacesetters was set up in 2008 to address the health needs of the local Roma community which is the largest in the UK, with around 900 families. The main objective of the project has been to increase the number of Roma people registered with a GP. At the same time, it has also worked to improve the Roma community's awareness of health issues and build NHS Newham's confidence in dealing with them.

Working in partnership with the Roma Support Group (a third sector organisation committed to improving the quality of life of the Roma), the project has brought together a range of professionals from across clinical, acute care, mental health, education and other backgrounds to work towards better health outcomes for the Roma community in Newham.

### Service provision

The NHS Newham Pacesetters has employed a range of innovative methods to engage people with the project:

- **Roma Health Communication Worker:** Employed for two days a week and based within the Roma Support Group, the Communication worker is the central access point within the Roma community, offering individual help to people around health issues and conducting interviews to assess health needs
- **Cultural awareness programme:** Aims to raise awareness among NHS Newham staff of the culture, tradition and health needs of the Roma people and build confidence in dealing with them
- **Health event and MOT:** Held at the end of 2009 in conjunction with the Roma Support Group's AGM, the event highlighted health issues around smoking, diet and the heart. Attendees were also offered a health MOT which measured BMI, blood pressure and blood sugar levels
- **Transitional terms of registration:** Enables people to register with a GP with a proof of ID rather than proof of residence

### Promising practice

- ✓ **Focus:** The project has brought attention to a range of health issues which are often difficult to approach within Gypsy and Traveller communities
- ✓ **Partnership:** Central to the success of the project has been working in close collaboration with the Roma Support Group
- ✓ **Professional development:** As well as improving the health awareness of the Roma community, an essential element of the project has been to build the knowledge and understanding of the NHS staff so that they can address the particular needs and challenges of the Roma community effectively and with sensitivity
- ✓ **Innovation:** Working with the Roma Support Group, the project has been able to introduce health issues – often a taboo amongst the community – against a backdrop of community and cultural events

# People with Learning Disabilities: demographics

## Definition

The spectrum of learning disabilities is large, ranging from very mild to severe. Officially, people with learning disabilities are defined as having:

- A significantly reduced ability to understand new or complex information and/or learn new skills (impaired intelligence)
- A reduced ability to cope independently (impaired social functioning which started before adulthood, with a lasting effect on development)<sup>1</sup>

These impairments make it harder for people with learning disabilities to read, write and understand verbal instructions.

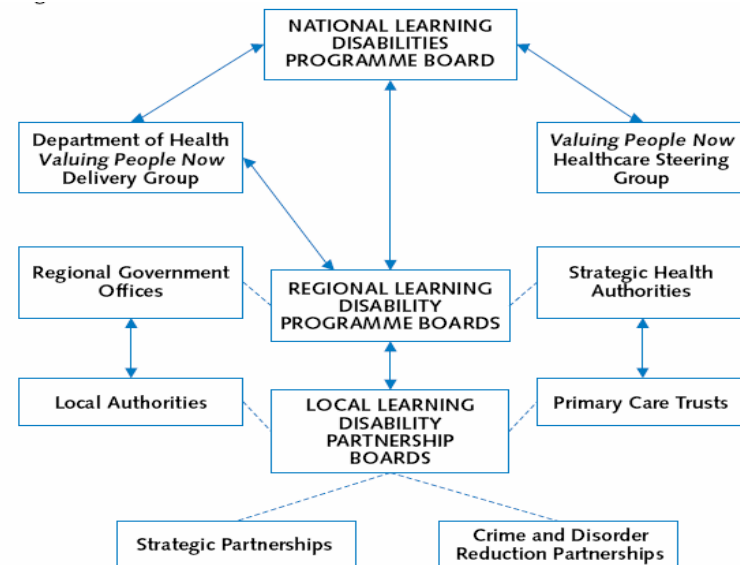
## Demographics

**Population:** No accurate records are kept of the number of people with learning disabilities in England. A 2004 figure estimated that there are about 828,000 people over 18 years with a learning disability in England<sup>2</sup>, 22% of whom are known users of disability services.

Modest but sustained growth in the numbers of people with learning disabilities of around 11% is expected over the next two decades<sup>3</sup>

**Nationality/ethnicity:** A Care Quality Commission census reports that 13% of learning disability patients were from black and minority ethnic groups<sup>4</sup>, compared to 8% in the general population<sup>5</sup>.

Following a number of high profile inquiries, the policy framework for learning disabilities and health is comparatively well-developed, with clear lines of accountability for the health and well-being of people with learning disabilities locally, regionally and nationally.



Some incentives have been introduced to monitor the health outcomes of those with learning disabilities, such as annual health checks, integration of learning disabilities into the NHS Operating Framework and via the Quality Outcomes Framework (QOF). The 2008-09 baseline was that 23% of those eligible received a health check. Whilst data is not available yet for 2009/10, a marked improvement is expected.

## People with Learning Disabilities: health and wider needs

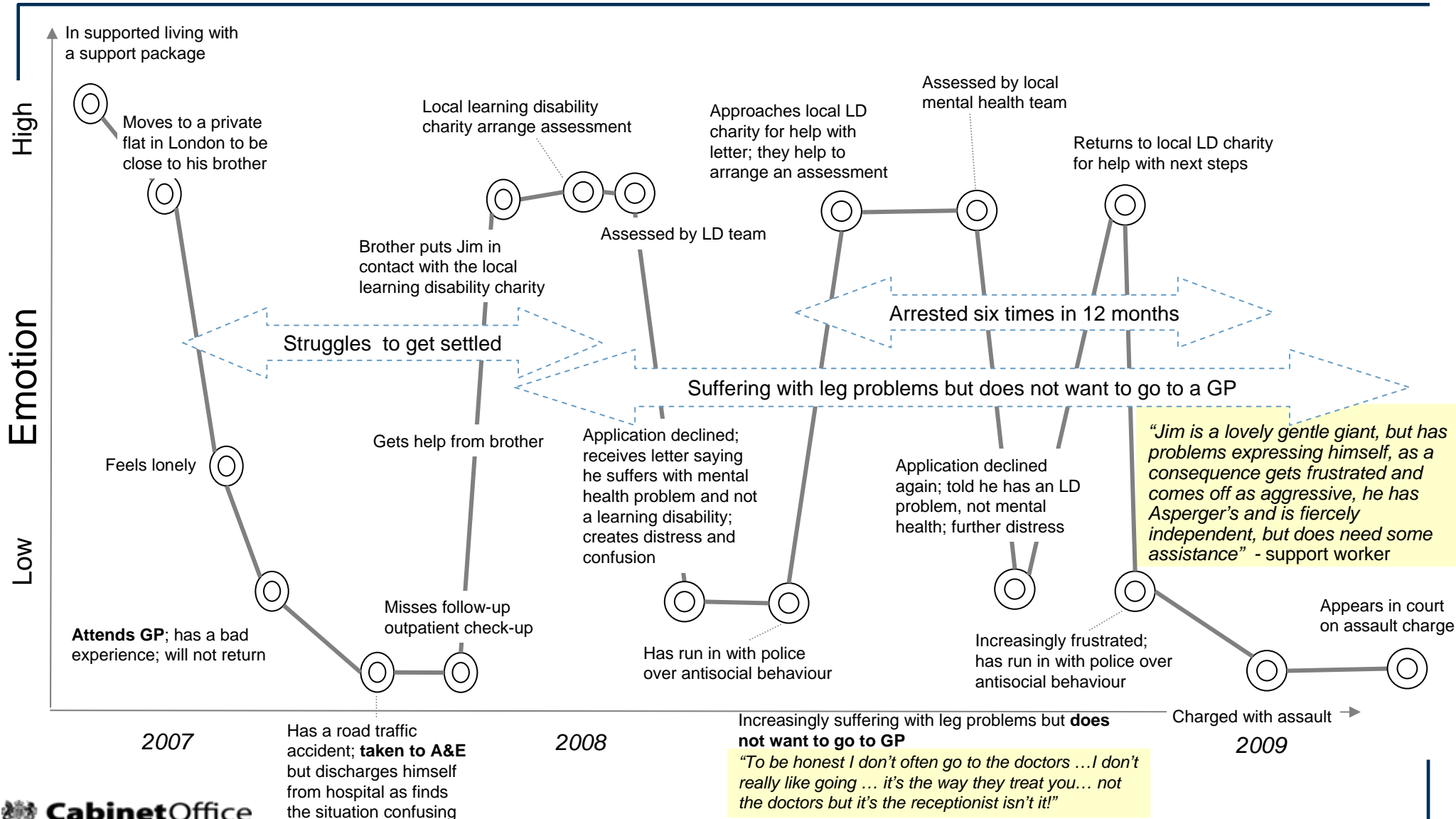
There is evidence that most people with learning disabilities have poorer health than the rest of the population

Health risks	Example of evidence	Social determinant	Example of evidence
Mental Health	<ul style="list-style-type: none"> <li>• Mental health problems are more common amongst adults with learning disabilities – prevalence of schizophrenia is around three times greater than for the general population.<sup>1</sup></li> <li>• 27% of respondents to the Adults with Learning Difficulties survey reported experiencing mental health problems<sup>2</sup></li> </ul>	Poverty	<ul style="list-style-type: none"> <li>• Severe learning disability is relatively evenly spread in the population. However mild to moderate learning disability rates are higher in some deprived and urban areas<sup>8</sup></li> <li>• People with learning disabilities living in private households are much more likely to live in areas characterised by high levels of social deprivation<sup>9</sup></li> </ul>
Osteoporosis	<ul style="list-style-type: none"> <li>• People with a learning disability tend to have osteoporosis younger than the general population and have more fractures<sup>3</sup></li> </ul>	Income and employment	<ul style="list-style-type: none"> <li>• The employment rate among those in receipt of adult social services is just 10% - although 65% of people with learning disabilities would like to get a paid job<sup>10</sup></li> <li>• Just 17% of people with mild/moderate learning disabilities and 4% of people with severe learning disabilities who were of working age reported earning more than £100 a week<sup>11</sup></li> </ul>
Respiratory disease	<ul style="list-style-type: none"> <li>• Three times more likely to die from respiratory disease<sup>4</sup></li> </ul>	Education and skills	<ul style="list-style-type: none"> <li>• Just over one in three people were undertaking some form of education or training. This was much higher among people with mild/moderate learning disabilities and severe learning disabilities than those with profound and multiple learning disabilities<sup>12</sup></li> </ul>
Heart Problems	<ul style="list-style-type: none"> <li>• Higher risk of coronary heart disease than the general population and is the second most common cause of death in people with learning disabilities<sup>5</sup></li> </ul>	Housing	<ul style="list-style-type: none"> <li>• The majority of people with learning disabilities, both mild and severe, live with a parent. People with more severe learning disabilities are more likely to be living in Residential Care Homes and NHS accommodation<sup>13</sup>.</li> </ul>
Physical Disability	<ul style="list-style-type: none"> <li>• Up to a third of people with learning disabilities have an associated physical disability<sup>6</sup></li> </ul>	Lifestyle and behaviours	<ul style="list-style-type: none"> <li>• 30% of those with mild/moderate learning disabilities reported smoking; 11% of those with severe learning disabilities and 4% of those with profound and multiple learning disabilities<sup>14</sup>.</li> </ul>
Weight	<ul style="list-style-type: none"> <li>• People with learning disabilities are more likely to be over or underweight e.g. 32% of women with LD are obese, compared with 23% of women in general population and 19% of men with learning disabilities were underweight compared with 2% of men in the general population<sup>7</sup></li> </ul>		

People with learning disabilities are **58 times more likely** to die before the age of 50 than the general population.<sup>15</sup>

# Case study

## Jim – late 20s – lacks support and struggles with managing daily life



## People with learning disabilities: summary of access and quality

Issue	Supporting evidence
<p><b>Institutional factors:</b> difficulty registering and making appointments, navigating the system etc</p>	<ul style="list-style-type: none"> <li>• Diagnosis of learning disabilities is often dependent on identification at school, and that information can often be lost on transition into adulthood</li> <li>• Access to appointments is difficult without advocacy – literacy problems and/or communication barriers can make things like form filling and/or calling a major obstacle. Language and accents of staff can also be difficult for people with learning difficulties<sup>1</sup></li> <li>• Feelings of anxiety can grow if waiting for long periods of time in waiting room<sup>2</sup></li> <li>• People with learning disabilities do not necessarily plan to get double appointments when they might need them</li> </ul> <p><i>“Sometimes when I receive letters, I don’t understand them...I don’t really know what is going on...I will get my keyworker to explain” - Faye, late 30s (SETF, 2009)</i></p>
<p><b>Lifestyle and behaviour:</b> reluctance to engage; often don’t self-identify</p>	<ul style="list-style-type: none"> <li>• People with mild to moderate learning disabilities may not be known to services and reluctant to seek out health care; half seek out hospital doctor; half families and friends when they need to address health issues<sup>3</sup></li> <li>• Parents and carers often act as advocates and helpers. In some cases, they can also inhibit people with learning disabilities from accessing healthcare</li> <li>• Often communication difficulties or diagnostic overshadowing can lead to a delay in symptoms being identified and treatment sought</li> </ul>
<p><b>Service provision:</b> diagnostic overshadowing, exclusion screening, workforce training etc</p>	<ul style="list-style-type: none"> <li>• SETF research highlighted that some healthcare staff have limited personal experience of people with learning disability as their numbers are relatively small. This can lead to assumptions that physical healthcare needs are an aspect of the individual’s learning disability so require no further examination or treatment.</li> <li>• There are reports of people with learning disabilities being excluded from regular or universally offered exams/screening, often due to health care professionals not having the confidence/experience of treating/screening people with learning disabilities<sup>4</sup></li> <li>• There continues to be a reluctance, especially among GPs, to take up further training on learning disabilities</li> </ul> <p><i>“There are still massive taboos around people with learning disabilities accessing sexual health – sexual health nurse” – Pearl (SETF, 2009)</i></p>

# Promising Practice

## Model 1: Pearl Sexual Health service

### Background



The Pearl Sexual Health service is a dedicated, easy access 'mini' service for people with learning disabilities. Launched in 2008, it is one of the few dedicated services in the country and runs at no additional cost from mainstream funds.

The service is located within the West London Centre for Sexual Health at Charing Cross Hospital in London and, as with mainstream services, is open to all regardless of where clients live.

This service was set up by mainstream workers at the sexual health clinic as a response to a distressing case in which a client with learning disabilities had been raped and the mainstream sexual health service struggled to meet her needs.

Practitioners at the Centre asked themselves the question "what can we do to make it easier for people with learning disabilities who need to access the centre?".

### Service provision

The Pearl service attracts just one or two clients per month and is actively building its profile to raise awareness of the range of services it provides:

- **Trained professionals:** Clients can self refer to the clinic or be referred by a GP, family member, carer, case worker or social worker (with the client's consent). The staff at Pearl, from receptionists to practitioners, have received training and advice on learning disabilities from specialist workers to ensure they understand client needs
- **Pre-appointments:** Offered to familiarise clients with the environment and examination, before returning at a later date for their appointment
- **Health prevention:** Including screening for sexually transmitted infections, hepatitis B vaccinations, contraception and HIV tests
- **Health promotion:** Clients, who can be accompanied by a care worker or family member, will have a sexual health exam and discuss their needs at the clinic with a nurse or doctor

### Promising practice

- ✓ **Focus:** The service was developed by a mainstream practitioner who recognised an unmet need and brought together existing resources to meet it
- ✓ **Partnerships:** Crucial expertise and advice about how to shape the service was supplied by the local Learning Disability partnership and a group of people with learning disabilities
- ✓ **Professional development:** Through training from specialist workers, the workforce is supported to provide appropriate care for its clients
- ✓ **Personalisation:** By adopting simple adjustments, such as direct access to the health advisor teams via the telephone, careful use of language when communicating with clients, pre-appointments to help client orientation and double appointments
- ✓ **Innovation:** Sexual health remains a taboo area for those with learning disabilities, this service overcomes those taboos to provide mainstream sexual health services, adjusted to the needs of those with learning disabilities

# Promising Practice

## Model 2: Elfrida Society Access to Health project

### Background



The Elfrida Society's Access to Health project was established in 1994 to support adults with learning difficulties access health services.

Clients are referred by care workers, support workers or other voluntary services and the project is now at full capacity, with a 6 month waiting list for referrals.

The project is staffed by two full-time posts and 1 part-time post. One full-time post is jointly funded by the London Borough of Islington and Islington NHS, another is funded by a the National Lottery fund.

### Service provision

The Access to Health project covers four main areas:

- **Health promotion:** Encouraging clients to keep fit and healthy via their sports project which supported 89 people into 129 projects between April 2008 – July 2009. They also organise workshops about sexual health and relationships, a service unavailable anywhere else in the borough
- **Health information:** Often translating complex information from mainstream services into language that people with learning difficulties can understand, providing bespoke information on specific conditions with input from service users in the design process. They also carry out consultancy work on national literature for the NHS
- **Advocacy:** Supporting clients with registering complaints, making appointments and accompanying them as required
- **Training:** Offering training to medical professionals and local health services to encourage more accessible provision for those with learning disabilities

### Promising practice

- ✓ **Advocacy:** Demonstrating tenacity and persistence to navigate the health system on behalf of their clients, representing clients so that their health needs are met effectively
- ✓ **Personalisation:** Taking the time to engage with clients, building trusted relationships in order to understand the needs of the individual
- ✓ **Partnerships:** Working successfully with the community dental service, district health nurses and the PCT as well as other voluntary projects
- ✓ **Voice:** Linked into the Valuing People Board at Islington Council and involved in the development of polyclinics and local health assessment rollouts to ensure those with learning disabilities have a voice at a strategic level
- ✓ **Recovery:** Providing a holistic service by linking up with broader initiatives that help clients with employment, housing and education

*"Most of what we do could be integrated into the PCT, however there will always be a role for the third sector to act as independent advocates for clients. At the moment there are pockets of good practice across the country but it's still a health lottery for people with learning disabilities."* – Elfrida Society (SETF fieldwork, 2009)

# Promising Practice

## Model 3: Walsall Pacesetters project

### Background



### Walsall Community Health

The Department of Health's Pacesetter programme aims to deliver equality and diversity improvements and innovation.

Local evidence in the West Midlands showed that uptake for breast screening services by women with learning disabilities in Walsall was much lower than the general population. Failure to attend screenings was often due to apprehension and the majority of service users who did attend a screening found the process distressing, and so failed to attend future appointments.

To this end, the Walsall Integrated Learning Disability Service (as part of the Pacesetters programme) developed a service aimed at increasing the number of women with learning disabilities undergoing breast screening.

### Service provision

Based on this evidence, the Walsall Integrated Learning Disability service set about changing current service provision to meet the needs of women with learning disabilities:

- **Identification:** The service gained access to the database of registered patients and manually identified those with learning disabilities by cross-referencing with the Learning Disability service caseload, which is now regularly updated
- **Targeted communications:** The identified women were then sent easy to read letters encouraging the uptake of preventative breast screening
- **Raising awareness:** The service ran several health education groups e.g. 'Looking after our bits' to raise awareness of breast and cervical screening
- **Improving quality and access:** Service users were offered 20 minute appointments to allow time for familiarisation with the radiographer as well as providing clear and full explanations. Pre-appointments were also made available and facilitated by a learning disabilities nurse and radiographer to discuss the procedure and see the machinery in action

### Promising practice

- ✓ **Advocacy:** Due to the advice and support provided, all of those who had previously failed to attend a screening went on to attend
- ✓ **Personalisation:** Walsall Integrated Learning Disabilities service engaged with female service users to enable them to contribute to the design and delivery of services. By understanding the needs, fears and difficulties of women with learning disabilities the service could address them in order to create provision responsive to client need
- ✓ **Evaluation:** There were 160 women eligible for breast screening out of a population of 950 people with learning disabilities. Of these, 40% successfully attended (for a fifth of those, this was their first screening episode)



# Promising Practice

## Model 4: Westminster PCT Community Dentistry

### Background



A local baseline audit of GP registers of patients with learning disabilities in Westminster PCT revealed that of 233 people only about 10% had a record of their oral health and only 4% had seen the dentist in the last year (Westminster 'The Big Plan' JSNA).

Combining this survey with the Local Enhanced Service for Learning Disability, Westminster identified at least 25% people with learning disabilities had not been seen within the last year. Of those seen by a dentist, 35% were seen within the Community Dental Service and 35% by a local general dental practice.

### Service provision

As a result the Community Dentistry team looked for solutions to improve oral health and awareness amongst clients with learning disabilities, as well as carers and support workers, identifying key barriers and re-designing the service to encourage greater participation:

- **Tailored approach:** A team of two dental therapists reviewed the dental pathways of clients with learning disabilities and took a targeted and tailored approach. This involved contacting people with learning disabilities, encouraging them with accessible literature to register with the Community Dental Service and attend regular check ups.
- **Making the case with carers:** One of the key barriers identified to good oral health for people with learning disabilities is that carers often do not like going to the dentists themselves.

*'A patient had six teeth but hadn't been receiving the help to brush because her carers hadn't checked to see if she had any'* — Community Dentist (SETF 2009)

### Promising practice

✓ **Evaluation:** The outreach work by the Community Dentistry team successfully increased uptake of dentistry service by clients with learning disabilities. Of 231 people contacted by the team, 225 attended appointments

✓ **Focus:** The role of dental therapists on the team has been invaluable. They have the skills and experience to work with vulnerable people and have proactively built relationships with local organisations and made contact with people with oral health needs. The dentist had successfully led on similar work elsewhere.

✓ **Partnerships:** Needs assessment and strategic leadership from the Westminster Learning Disabilities partnership helped drive the project.



# Promising Practice – Services that engage with a range of socially excluded groups

## Model 1: Open Door, Grimsby

### Background



One of only 22 projects to be awarded 'pathfinder' status, Open Door was initiated by North East Lincolnshire PCT as a local social enterprise. It provides a broad spectrum of services aimed at improving the quality of life of the vulnerable and marginalised people in North East Lincolnshire who do not access mainstream health services.

The motivation for the initiative came in 2003 after two specialist health visitors recognised that around 1000 people in the area were not registered with local GPs.

Open Door has dramatically improved the lives of vulnerable and marginalised groups who are more concerned with core needs, such as food and shelter, than they are with their health.

Funding: Open Door receives income of approximately £360,000 per year

### Service provision

The project provides a wide range of general health and social care services including:

- **Health trainers:** Help with many aspects of maintaining a healthy lifestyle, offering advice in diet, exercise and giving up smoking
- **Hearing clinic**
- **Holistic therapy and acupuncture**
- **Basic life skills classes** help to improve reading writing and numeracy skills
- **Men's and women's groups:** Offers chance to discuss a wide range of lifestyle issues
- **Counselling sessions**
- **Group anger sessions**
- **Nintendo Wi-Fi afternoons:** Helps bring together people socially and promote physical activities
- **CAB benefits:** An adviser comes to give guidance on all aspects of benefits, including job seekers, disability living allowance, income support, and housing
- **ESOL language classes**

### Promising Practice

- ✓ **Recovery** e.g. English language classes, access to Citizen's Advice Bureau, holistic and alternative therapies, as well a nearby medical centre
- ✓ **Advocacy** e.g. accompanying patients to A&E and other appointments to improve access and compliance
- ✓ **Partnerships:** The centre has developed strong relationships with many local stakeholders e.g. the local hospital's A&E department now automatically refers patients to Open Door if they are not registered with a GP
- ✓ **Personalisation:** Community input into design of services has been critical to its success. Service provision is constantly evaluated and re-designed it to ensure client's needs are met
- ✓ **Supportive:** Open Door provides a safe and secure setting which encourages people to come together for mutual support

*"We won't turn anyone away. It's about them, not just their health"* – Open Door Ethos

Starting with 23 patients, Open Door has now registered 850 patients – 190 of which have been returned to mainstream services in the past two years

# Promising Practice – services that engage with a range of socially excluded groups

## Model 2: The Quays Medical Centre, Hull

### Background



TOGETHER WE CARE

**The Quays Medical Centre** was established in 2001 as a Personal Medical Services (PMS) pilot in recognition that a sufficient population of patients in Hull did not have adequate access to health care services. It not only provides general medical services, but complex treatment teams also deal with more chaotic clients to provide short, intensive interventions. These clients include clients with drug and alcohol problems, asylum seekers and refugees, commercial sex industry workers, homeless, patients with mental health problems and patients unable to be managed in other GP surgeries.

The initial objectives of the pilot were:

- Improving access to appropriate and effective care for the target groups of patient
- Better integration of primary care with community and secondary care
- Development of strong and sustainable partnership working

It runs at annual costs of £530,800, or £300 per patient. Services are primarily commissioned by Hull PCT and receive additional funding from East Riding to accept violent patients.

There are currently 33 staff, 19 of whom are employed by West Hull PCT. The remainder are employed by either the community trust or a non-statutory agency. The staff manage approximately 1,758 registered patients, of which 137 are homeless and 319 are asylum seekers/refugees.

### Promising Practice

- ✓ **Professional development:** ‘Shared’ posts allowing clinicians to work at the Quays and other clinical settings good for staff retention and preventing burnout
- ✓ **Personalisation:** Co-location of services, for example, patients have access to a local addiction service, an appointment system that is responsive to more immediate demands meet client need. Staff consistently use the same clinical system across all client groups, building trusted relationships with clients to ensure that the client feels supported
- ✓ **Voice:** The Quays Medical Centre works to raise the profile of inclusion medicine as a sub-specialism
- ✓ **Evaluation:** The medical centre encourages feedback from clients informally throughout the year, and also via an annual client survey which then feeds into the patient forum

# Promising Practice – services that engage with a range of socially excluded groups

## Model 3: Charing Cross Hospital Centre for Health

### Background

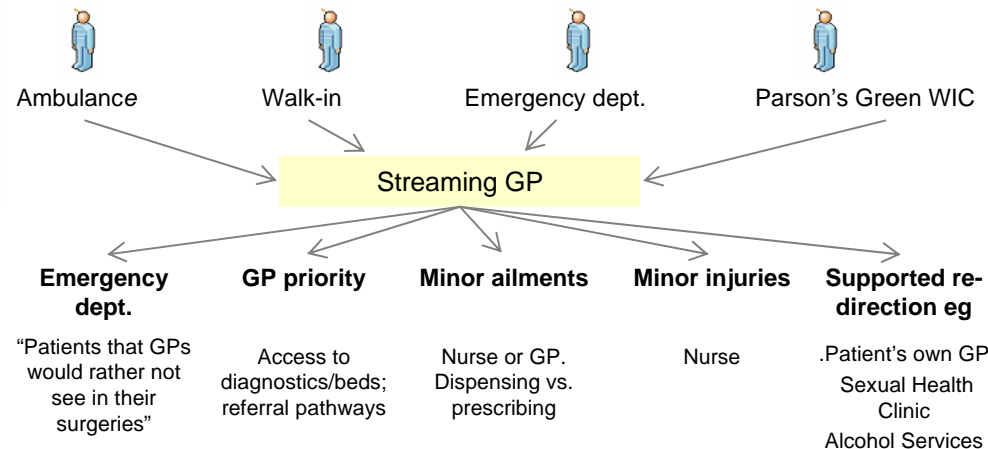


The Centre for Health was introduced to Charing Cross Hospital in September 2009 in response to clients with primary health care needs inappropriately accessing acute services (A&E). The Centre for Health tackles this by ensuring that these patients are seen by a primary care clinician at a time and place that is convenient to them, improving client waiting times and access.

Since inception, the Centre for Health has seen approximately 60% of all A&E attendees. While A&E departments often focus on treating the presenting problem with, traditionally, little follow-up care, this innovative model enables clients to get the appropriate treatment and continuity of care, freeing up A&E staff to deal with the more seriously ill and injured.

When patients present with unplanned care needs they are met by an experienced GP who, using streaming guidelines, rapidly assesses the patient to exclude life threatening conditions, or significant trauma (in this case they are urgently transferred to the Emergency Department). The GP will then decide in which of the four remaining streams the patient's care will be best delivered.

After an initial assessment, clients are directed to the appropriate services to meet their health needs.



### Promising Practice

- ✓ **Innovation:** By recognising that a significant proportion of clients were attending A&E, while actually presenting with primary health care needs, Hammersmith and Fulham PCT took the opportunity to build new services around these “touch points” in order to maximise opportunities for longer-term care and advice.
- ✓ **Partnerships:** The Centre for Health combines efforts from London Central and West Unscheduled Care Collaborative Imperial College Healthcare NHS Trust, Central London Community Health and Imperial College.

# Promising Practice

## Model 4: Personal health budgets

### A shift in power

Personal health budgets offer clients the opportunity to shape their care to suit their needs, encouraging service provision that is responsive to client need and preference. This approach has the potential to deliver better care outcomes by improving the quality of care and client experience.

They can be offered using a spectrum of models:

**Notional budgets:** Clients are made aware of options available within the budget constraint. The NHS retains all contracting and service coordination functions

**Third party budgets:** Personal budget held by an intermediary on the client's behalf e.g. an Independent User Trust

**Healthcare direct payments:** The goal would be for the individuals to be given cash payments instead of service entitlements and purchase and manage services themselves, with appropriate support [not currently legal]

Evidence drawn from social care and international health systems suggests that the increased self-direction offered to clients can:

- Improve wellbeing by promoting a more preventative approach to care
- Reduce the use of acute interventions such as crisis support
- Encourage a more flexible response from providers and
- Strengthen choice and contestability within community settings

### A potential case for change

The Department of Health is currently piloting personal health budgets over a three year period (2009 – 2012) across 70 different sites. The sites chosen cover a range of client conditions and demographics, including age, ethnicity, disability and socioeconomic status, as well as rural and urban areas.

20 of the sites will undergo an in-depth evaluation covering:

- Effects on quality of care
- Wider behavioural effects
- Financial effects and impact on the cost-effectiveness of services
- Effects on the wider NHS, including existing services
- Ease of implementation

Until this evaluation is complete, it is hard to establish whether this model will produce financial savings. However, prior experience in social care and from elsewhere in the world suggests that this **will not be increasing costs** as it is anticipated that the costs incurred in planning and personalisation of care will be offset by cost savings from reduced resource use.

For socially excluded clients, who often require more personalised care pathways, this shift away from the traditionally uniform delivery models currently offered could produce significant improvements to health outcomes provided the necessary support is in place to help clients navigate the various models.

Increasing degree of autonomy given to patients

## Promising Practice – community pharmacy and oral health

### Community pharmacies

Pharmacies provide a convenient and less formal environment for a wide range of services, such as: chlamydia screening; stop smoking services; needle and syringe exchange services; weight management services; supervised administration of methadone; emergency hormonal contraception.

99% of the population (including those living in the most deprived areas) can get to a pharmacy within 20 minutes by car and 96% by walking or using public transport.

#### Isle of Wight NHS Hepatitis B and C Dry Blood Spot Testing and Hepatitis B Vaccination Service

Integrating community Pharmacists into the care pathway of injecting drug users to undertake Hep B&C testing and vaccination linked to supervised methadone consumption has led to:

- Improved uptake of vaccines
- Patients being identified with undiagnosed Hepatitis B and/or C infection
- Infected patients signposted into secondary care services
- Collaborative working with the Island drug and Alcohol, and sexual health services
- Priority referral arrangement
- HIV screening service

#### Promising Practice

✓ **Personalisation:** Modelled on convenience to the client, rather than to the service. It includes reasonable adjustments such as priority referrals and faster vaccination schedules

✓ **Partnerships:** Good links with secondary care services (sexual health) to treat the breadth of client need

### Oral health

Evidence tells us that the higher the socio-economic group, the more likely people are to see the dentist regularly and that specific groups have traditionally lower use of dental care services e.g. people with learning disabilities, people with mental health problems and BME groups (there is evidence of higher rates of oral cancer among South Asian men).

Special efforts are required to make dental care services available to socially excluded groups and to encourage uptake among deprived communities.

#### Great Chapel Street Medical Centre

Great Chapel Street offers an integrated model of care with a full multidisciplinary team to help reduce health inequalities amongst the homeless. Amongst the wide range of health and social services offered to clients, there is a dentist and dental nurse on site 2 days per week.

The dentistry service provided is crucial as homeless clients will often not have access to General Dental Practices (GDPs). Whilst cancellations are high, those who do attend appointments are usually in desperate need of urgent dental care – highlighting the need for the service. It also gives the dentist further opportunities to refer the client onto wider health and social services that he might need.

#### Promising Practice

✓ **Partnerships:** Working with a range of third and health sector partners to provide broad services in-house and strong links to other services

✓ **Recovery:** Multiple services housed under one roof maximises the opportunity to treat more than just the presenting problem

## Promising Practice – International models

### Inner City Health Program (ICH) – St. Michael's Hospital, Toronto, Canada<sup>1</sup>

The ICH aims to provide high-quality and holistic primary, secondary and tertiary care for highly marginalised and at-risk groups, such as the homeless, at-risk women and children, people with severe and persistent mental illness and addictions.

#### Innovative Solutions

- *Homeless pathway methodology* determines the client's living situation and, based on this, screens for other common problems amongst this population. They address these concerns and then create a discharge plan working closely with shelters to ensure continuation of care and follow-up.

- *Mobile Crisis Intervention Team* which includes a psychiatric nurse and police officer who respond to emergency calls – this has helped to reduce 73% of admissions to hospital or jail.

#### Promising Practice

- ✓ **Partnership working** with community and charitable organisations to deliver a comprehensive package of care and support
- ✓ **People-centred design** via the Community Advisory Panel (which includes service users) that feed into service design and planning
- ✓ **Research and evaluation** is carried out by the Centre for Research on Inner City Health, which gathers evidence and learning about how best to address health inequalities amongst those most vulnerable.

### Kings of the Street: Improving Homeless Health project – Slovenia<sup>2</sup>

The project has two main aims:

1. To prevent and reduce poor health outcomes amongst homeless individuals and;
2. To work with public health and care services to engage this group.

The programme works with those that are chaotic and extremely vulnerable, many of whom are not in touch with mainstream services and have alcohol and drug addictions. It offers an holistic approach to improving the health for these people by assisting with resettlement and pathways back to work, as well as promoting healthier lifestyles. It works with individuals to connect them with health care services, promote positive health behaviour and empower clients to help themselves.

#### Promising Practice

- ✓ Looking beyond presenting symptoms, to help the client with **health and wellbeing** needs together with social and economic factors
- ✓ **Flexible services** tailored to the service user's needs by means of a drop-in centre open 6 days a week
- ✓ **Partnership and advocacy** work with clients to assist them in navigating their care pathway

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# Service models span mainstream-specialist and medical-social axes

There are a range of service models that provide promising care for socially excluded groups:

## Great Chapel Street Medical Centre

Providing a wide range of services for the homeless, including GP, psychiatric, dentistry, nursing, counselling and podiatry as well as linking to social services such as housing, benefits and legal advice. Staff take advantage of clients presenting with a health need, using these 'touch points' to refer clients to other members of the team. This maximises the Centre's opportunity to treat the breadth of the client's health needs, rather than just the presenting problem.

In-reach or outreach clinical teams identifying, supporting and treating key vulnerable groups or individuals. May take holistic approach

Close links or co-location of primary and specialist/care services within traditional medical care settings

## Medical

Traditional primary care networked within supportive mental health, substance misuse and care services

Specialist primary care, nurse or GP led, close commissioner support. Often strong links with other practices, specialist treatment and care services

Complex medical and social care provider. Multiple in-house services linked to local specialist treatment services

## Centre for Health – Charing Cross Road Hospital

By recognising that a significant proportion of clients were attending A&E, whilst actually presenting with primary health care needs, Hammersmith and Fulham PCT took the opportunity to build new services around these "touch points" in order to maximise opportunities for longer-term care and advice. The Centre for Health links with other health services.

## Specialist

## ASGARD

Based in North East Lincolnshire, the service has a caseload of just over 650 young people who are either at risk or already experiencing health and social care inequalities. Through proactive engagement with 16-19 year olds, ASGARD support workers assist service users in navigating their care pathway, providing advocacy and support in interactions with a wide range of medical and social services.

Joint commissioned health and care provision, based in area of greatest need. Focus on wider needs not underlying diagnosis

Outreach approach which builds trust and engagement of clients with services

## Mainstream

## Bromley by Bow Centre

A community organisation based in East London, the centre works to support the local population through delivery of a wide range of services e.g. employment, welfare and debt advice, healthy living centre, education and skills and social enterprise. The centre's mission is to "help to create a cohesive, healthy, successful and vibrant community and to remove the label 'deprived' from Bromley by Bow." Vital to the centre's success is partnership working across a range of local services, Tower Hamlets PCT and The GP Partnership.

Closely networked local services with shared case loads, outreach teams able to work across boundaries with good medical support, linked to primary care

Range of social and health services, including the Third Sector, leading community-based responses with supportive primary care

## Social

## 'Golden Threads' – common features across the models

We distilled six key 'golden threads' from our fieldwork:

### The service offer

### The client experience

#### FOCUS

Effective services work well with commissioners to highlight the health needs and outcomes of socially excluded groups.

**I know there'll be help and it won't disappear**

#### VOICE

Local leadership and tenacity within mainstream services, the third sector and in wider agencies can make real improvements happen. An effective advocate can be key to ensuring that health services treat the person rather than the condition.

**I feel like I have the support of people who care and will stick by me**

#### PERSONALISATION

Building an understanding of the needs, beliefs and values of the patient is essential for successful services – this includes involving clients in designing and improving their own services. Being client focused can also mean being aware of and actively managing expectations, and being prepared to promote flexible and tailored responses where appropriate.

**I'm involved in decisions about my care. People understand my specific needs**

#### QUALITY AND INNOVATION

Ensuring quality services means building evidence and collecting data from scratch as well as using links with their partners who have information and knowledge.

**My care is effective and coordinated**

#### RECOVERY

Beyond addressing the immediate needs and conditions of clients, services given the necessary support to prevent the same patterns and problems recurring. As well as ensuring continuity of health provision, this can also include help with accommodation and training, so that clients can go on to live healthy and fulfilling lives.

**They care about my wellbeing and believe I have a future**

#### PROFESSIONAL DEVELOPMENT

Practitioners have understanding of issues facing socially excluded groups and why and how they may react or behave differently to other people. Training can instil confidence in practitioners and better enable them to improve a client's health while building up trust.

**Staff know how to deal with me and really want to help**

## In practice, these ‘golden threads’ translate into a set of key service characteristics

Golden thread	What the service offer means in practice...
<b>Focus</b>	<ul style="list-style-type: none"> <li>• Clear objectives and outcome measures, which are agreed with commissioners and other stakeholders</li> <li>• Excellent knowledge of, and regular input from, their clients to inform service design, delivery and metrics</li> </ul>
<b>Voice</b>	<ul style="list-style-type: none"> <li>• Use a range of methods to ensure user involvement even where these people and groups are hard to engage with. This includes:               <ul style="list-style-type: none"> <li>– Designated champions and dedicated advocates</li> <li>– Peer advisory groups, expert patients and health ambassadors</li> <li>– Working across boundaries to maximise knowledge, capacity and influence</li> </ul> </li> </ul>
<b>Personalisation</b>	<ul style="list-style-type: none"> <li>• The service is flexible and tailored to meet and be sensitive to the particular needs, behaviour and values of patients</li> <li>• Clients are actively engaged in the design of their own care</li> <li>• Service adjustments, such as thoughtful, easy read leaflets and alternatives for form-filling, easy to complete forms and information</li> <li>• Use of individual and personal budgets</li> <li>• Services are delivered in comfortable and relaxing settings which are accessible for clients</li> </ul>
<b>Quality and innovation</b>	<ul style="list-style-type: none"> <li>• Use of research and evidence in service design, delivery and adjustment</li> <li>• Collaborating with partners to share knowledge and devise joint solutions and clear measures of quality</li> <li>• Use of ‘touch-points’ to engage patients wherever they present and to offer opportunities for accessing the wider range of services they may need</li> <li>• Culture of continuous evaluation, review, adjustment and improvement</li> </ul>
<b>Recovery</b>	<ul style="list-style-type: none"> <li>• Services not only treat clients’ immediate health symptoms but also address their long-term conditions, wider lifestyle needs and choices to improve chances of living healthy and fulfilling lives</li> <li>• Providers take a ‘holistic’ view of health and wellbeing and offer a wide range of services such as counselling sessions, basic life skills classes and access to the local housing services</li> <li>• Services which seek longer term goal of mainstreaming clients including a clear focus on prevention</li> </ul>
<b>Professional development</b>	<ul style="list-style-type: none"> <li>• Set up and operate as ‘learning organisations’</li> <li>• The provision of effective, continuous human rights, equality and diversity training and development for practitioners, with a particular emphasis on understanding the cultures of the socially excluded groups they are most likely to encounter in their local area. Ensuring that staff are more confident and knowledgeable in dealing with certain groups</li> <li>• Reflective practice, supervision and support networks (across and within professional groups; and across mainstream and specialist services)</li> <li>• Shared posts and rotations to prevent burnout</li> </ul>

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# The economic case

Annually, PCTs spend over **£60 billion** on medical and community health services.<sup>1</sup> Of this, socially excluded groups often incur disproportionate costs per person compared to the general population owing to their complex needs. However, there are few accurate costs on actual spend per disadvantaged group, partly because needs overlap between groups. In an increasingly challenging economic climate the temptation might be to overlook the more vulnerable groups. While there is a clear moral case for improving access and quality of primary health care for marginalised groups, it is often difficult to assess the cost effectiveness of current service provision as data on healthcare spend on socially excluded groups is lacking. Despite this, emerging evidence suggests that there is an economic case for intervention.

## The case for change

By changing the way we deliver services, savings can be made. While the options below should not be taken as a solution in all circumstances, they identify three key ways of delivering potential cost savings:

### 1. Effective design

Innovative, people-centred design and commissioning of services could produce significantly better health outcomes for the most vulnerable by recognising the challenges presented by socially excluded groups and tailoring services to meet their needs.

### 2. Efficient delivery

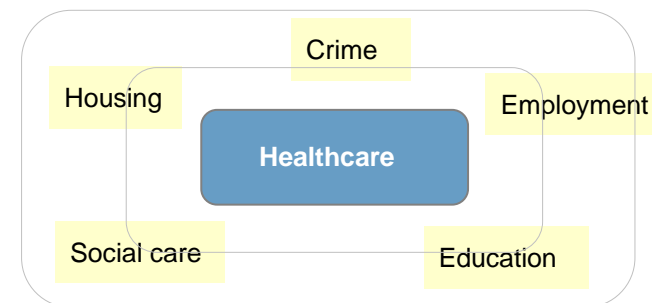
Health service provision to socially excluded groups can often be disjointed. By coordinating services, providing a holistic approach based on the full extent of client need, the quality of healthcare can be improved and efficiencies made.

### 3. Early intervention

Early intervention is often key to preventing longer-term, more costly health problems. Investment at an early stage can produce savings over the long-term.

## Wide reaching and long lasting

Costs associated with the health needs of the UK population extend beyond primary health care:.



*Fair Society, Healthier Lives* estimates that improving health inequalities would save:

- £31-33bn per year in reducing losses in productivity
- £20-32bn per year in welfare payments and lost taxes
- £5bn per year in NHS costs<sup>2</sup>

Socially excluded groups tend to experience complex and multiple health problems that require tailored and long-term solutions. As a result, it is often the case that the cost benefit of investing in these groups may not materialise immediately, but savings are likely to be made over the long-term.

# The economic case: effective design

## Effective Design: Needle and Syringe Programmes (NSPs)<sup>1</sup>

There are an estimated 130,000 – 200,000 injecting opiate/crack cocaine users in the UK that cost:

- **£35,000 per person** in healthcare provision over their lifetime
- **£445,000 per person** on related crime costs over their lifetime

People who inject drugs have an increased risk of contracting blood-borne viruses (HIV/hepatitis B/hepatitis C) as well as other illnesses such as injection-site infections. The risk of death among people who inject drugs is over ten times higher than for the general population.

**NSPs** provide sterile needles and syringes, as well as other equipment used to prepare and take illicit drugs. There are approximately 1700 NSPs operating in the UK – largely run by pharmacies and drug services. Whilst the NSPs provide a potentially controversial service, reviews have shown that they are an effective way to reduce some of the risks associated with injecting drugs and some of the costs.

Evidence also suggests that NSPs are the only contact that some people who inject drugs have with health services so they offer a vital opportunity to encourage them to:

- Stop using drugs
- Switch to less harmful forms of drug taking
- Opt for opiod substitution therapy
- Undertake testing for Hepatitis C and HIV

## Areas of saving

Preventing blood-borne viruses

Reducing A&E attendances and hospital day beds for injection site infection

Reducing the numbers of those who take/inject drugs

Reducing crime associated with illicit drug use

## Accidents and Emergencies

Research highlights that some socially excluded groups are more likely to access acute services than the general population, often inappropriately. Focusing on ensuring the best quality and most appropriate pathways for patients can improve health outcomes over the long-term and produce cost savings.

NHS Cornwall is an example of where this has worked, having saved **£1.7 million in 2008-09** by reducing emergency admissions in 15 conditions. Their strategy for reducing admissions included initiatives targeted at long term conditions, focusing particularly on self care.<sup>2</sup>

## QIPP: Quality, Innovation, Productivity and Prevention

The Quality, Innovation, Productivity and Prevention (QIPP) agenda aims to focus efforts on using innovation to improve the quality of patient care and to unlock productivity gains. Making QIPP a reality requires all levels of the system to design and implement more efficient services without compromising client care. Improvements are led at a local level, with incentives linked to specific quality goals. This enables clinicians to design services based on what is best for clients in their area, and should ensure that those with the greatest need (including socially excluded groups) get the best help.

## Total place – an example of efficient delivery

The Total Place agenda in 13 pilot areas encourages increasing frontline flexibilities to enable organisations to make efficiencies and improve services in appropriate and effective ways, focusing on the priorities that matter most. Key to this are collaboration and the design of services around the needs of individuals and communities, not institutions.

## The economic case: efficient delivery

### St Mungo's Health Strategy – integrated care

In *Health Strategy for Homeless People 2008-11*, St Mungo's proposes an integrated, holistic system of care that would be provided at the hostel level. It comprises several different elements which could be provided, introduced together, or built up over time starting with the health support worker and peer health champions. This is just one example of the new models of care which have been proposed for this client group. Others include forms of Intermediate care and the Complex Needs Patient Care Pathways being developed at UCLH. These forms of care try to better engage the homeless client group and have the potential to produce some cost efficiencies.

Summary of service provision and associated costs for a 60 bed hostel

	Service model includes	Resource requirements	Target outcomes include	Fixed cost per hostel	Variable cost per person
<b>Physical health</b>	Comprehensive health check, register with GP, on site nurse, screening	Health champion, health support worker	Reduction in A&E use and hospital admissions, reduced deaths, completing courses of treatment	£15,000	£890
<b>Mental health</b>	Psychiatric screening/ assessments, accessible psychological treatments, peer support	On-site specialist worker, trained specialist staff	No one with a mental illness to sleep rough, no suicides, extended provision of treatment programmes, increase number in work/training to 15%	£29,000	£967
<b>Alcohol</b>	Screening for hazardous drinking, AA on-site, Thiamine scripts/B12 injections available	On-site specialist worker, trained specialist staff	Reduced alcohol related deaths and admissions, reduced number of residents with an alcohol problem but not in treatment, increase number in work/training to 20%	£20,000	£941
<b>Drugs</b>	Initial screening/assessment, needle exchange, peer support, OD training, blood borne virus screening, on-site reduction programme	On-site specialist worker, trained specialist staff GP/ nurse prescriber support	Reduction in drug related deaths, reduction in offending, reduced number of residents with a drug problem but not in treatment, increase number in work/training to 20%	£47,000	£941
<b>Well-being</b>	Exercise/smoking cessation/ healthy eating, counselling, pathways to employment, relaxation programme	Qualified Pathways to employment & relationship counselling staff	100% access to smoking cessation programmes, 10% residents taking regular exercise, 10% residents in paid employment, increased satisfaction of those participating in client involvement	£26,000	£67

- St Mungo's estimate that this service model could be provided for about **£5,500 per person annually**. The physical health element could be provided initially about **£1,100 annually** although the benefits would be more limited\*

- Provision of a service such as this could **reduce** the amount which PCTs currently spend, e.g. on A&E visits and would produce **significantly improved** health outcomes in this traditionally hard to engage client group.

- It is estimated that PCTs currently spend **£2,500 per homeless person annually** on primary/secondary care and ambulance journeys. US Evidence\* suggests improved case management of homeless people reduced hospitalisations/A&E visits by 25-30%, suggesting savings in the order of £600 per person could be possible in the UK.

- Health benefits and increased life years have a high value to society:** NICE currently approves health interventions which cost £20-30,000 per full quality life year gained. On this basis, the St Mungo's model would be cost effective if it produced 1 extra full quality life year for every 4-6 people receiving the extra service.

- Additional benefits to the individual and savings to government from increased employment and reduced offending

\* While 83% ST Mungo's client group suffers from at least one of the following: alcohol dependency; drug problem; mental health problem or physical illness. Therefore calculations are not based on all clients needing to access all of the services provided, creating slightly lower cost estimates

# The economic case: early intervention

## Mental health

The NHS dedicates more of its annual budget on mental health than any other disease area<sup>1</sup> and it is estimated that the total cost of mental illness in the UK is £110 billion per annum:<sup>2</sup>

- £18 billion for health and social care
- £32 billion in output losses to the economy
- £60 billion in human costs of reduced quality of life

Yet, between 25-50% of adult disorders are potentially preventable with treatment during childhood or adolescence (Kim-Cohen et al, 2003).

There has been significant investment in this field, for example, the Improving Access to Psychological Therapies programme. However, the National Institute for Mental Health in England estimates that further improvements in mental health care could save as much as **£3.1bn p/annum (IDeA)**. Layard et al. (2007) estimate that the cost of implementing additional mental health services would be recouped within 2 years, through reductions in incapacity benefits payments, and the increase in taxes.

## Substance Misuse

Middlesborough Families First scheme, first introduced in 2006, delivers multiple support services for adults and families on substance use related issues. The range of advice, social work intervention and support provided includes carers support; parenting skills; family mediation; health promotion; and one-to-one support.

An independent evaluation found that this programme of early intervention has been successful in preventing children from entering care placements outside their families, **costing £6,555 per intervention, compared to £33,000 average cost of child in care – IDeA**

## Antisocial Personality Disorder (NICE 2009)

A practical example of how those savings is early intervention for those at risk of antisocial personality disorder, which affects about 3% of males and 1% of females in the UK. Studies also estimate that almost 50% of prisoners in the UK have the disorder.

A range of early interventions are recommended such as cognitive behavioural therapy (CBT) and functional family therapy for young people aged 12 –17 with conduct problems, a known precursor to antisocial personality disorder.

Expected benefits of early intervention include:

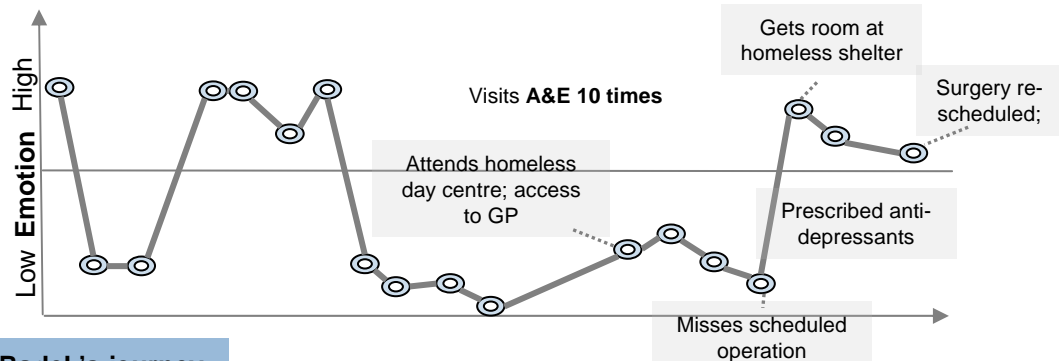
- Reduced costs in the emergency health services, education system and social care,
- Higher levels of staff retention,
- Reduced number of criminal offences, reduced policing and imprisonment costs
- Reduction in costs associated with lost employment opportunities, family disruption and relationship breakdown
- Reduction in costs associated with alcohol and substance misuse.

It is anticipated that the costs of prevention are **significantly less** than the costs of treating the effects of antisocial personality disorder. Especially when taking into account that:

- The average cost of holding someone in prison is £26,300 per year (figures from the Howard League for Penal Reform)
- 61% of all prisoners released re-offend within 2 years.



# The economic case: early intervention



Earlier, targeted intervention could generate cost savings both to the health sector and wider services.

Qualitative research carried out by the Social Exclusion Task Force in 2009, as part of this study, mapped the journey of Radek, a homeless person, through health and social care. Working on figures provided by Broadway homeless shelter and PSSRU Unit costs of health and social care (2008), estimates can be made on the potential savings of early intervention. **Our illustrative case below shows that savings from 35% upwards could be made.**

## Radek's journey

Ambulance costs x 10 @ £302 per incidence A&E costs x 10 @ £96 per visit	Satellite GP costs x 4 @ £72 per visit Day centre costs x 10 @ £40 per day	Missed op costs x 1 @ £1345 per incidence Shelter room costs x 12 @ £300 per week Claims DLA* x 12 @ £47.10 per week	Operation costs x 1 @ £1345 per incidence District nurse visits x 5 @ £73 per hour Shelter room costs x 6 @ £300 per week Moving on costs x 1 @ £5000 per incidence Claims DLA x 2 @ £47.10 per week Transfers to JSA x 4 @ £50.95 per week	<b>TOTAL</b> £18,986
<b>Sub-total: £3980</b>	<b>Sub-total: £688</b>	<b>Sub-total: £5510</b>	<b>Sub-total: £8808</b>	

## Illustrative journey with early intervention

Ambulance costs x 2 @ £302 per incidence A&E costs x 2 @ £96 per visit***	GP registration costs x 1 @ £54 Early intervention mental health team x 20 @ £28 per hour Shelter room costs x 8 @ £300 p/week Claims DLA x 8 @ £47.10 per week Referred to third sector organisation	Operation costs x 1 @ £1345 per incidence District nurse visits x 5 @ £73 per hour Shelter room costs x 4 @ £300 per week Claims DSA x 2 @ £47.10 per week Transfers to JSA x 2 @ £50.95 per week	Moving on costs x 1 @ £5000 per incidence Claims JSA x 2 @ £50.95 p/week before finding employment Settled permanent accommodation; working in full-time job; health improved	<b>TOTAL</b> £12,395 [potential saving £6,591]
<b>Sub-total: £796</b>	<b>Sub-total: £3391</b>	<b>Sub-total: £3106</b>	<b>Sub-total: £5102</b>	

\*DLA = Disability Living Allowance    \*\* JSA – Jobseekers Allowance

\*\*\*Ideally Radek would be referred to appropriate support on the first visit or, if not, then on the second visit to A&E

KEY: Health costs Wider costs

## The economic case: conclusions

A lack of data on cost effectiveness of service provision, together with variations in service provisions both in terms of range and breadth of services provided, makes it difficult to calculate return on investment. However, emerging data is encouraging and demonstrates the potential to provide better quality care for all at the same time as producing financial savings.

### ACE pilot case study: High need, high cost, intensive A&E usage<sup>1</sup>

**David** is a chronic alcoholic. He has liver damage, is immobile and has fluid on the lungs which leads to him needing a two-week hospital admission on a monthly basis. The police have to accompany the ambulance crew when they attend his house. No taxis will take him to A&E, so the ambulance is his main method of transport. He receives no support from social services, has been banned from respite care, and has no GP. He has been 'red-flagged' by the local PCT, which means he is not able to use their services owing to his aggressive/abusive behaviour. He often discharges himself from hospital without warning. He has a wide range of medication for his conditions, but does not take them. His condition deteriorates until he requires re-admission.

In the course of a year:

David calls the ambulance 2-3 times, 26 weeks of the year costing: **70 calls @ £263 = £18,410**

The Police attend each call: **70 calls @ £184 = 12,880**

Stay in hospital: **182 days @ £223 per day = £40,586**

**Total: £71,876 per annum**

### 1. Effective design

Innovative design of David's care package would mean a service that is centred around him, and not the system. Following a holistic assessment of his health and wider needs, David could be assigned a trusted practitioner to help him access the services he needs.

### 2. Efficient delivery

Efficient delivery of David's care would mean that the interventions he receives are sequenced in order to maximise a successful outcome, and delivered by the most effective provider.

### 3. Early intervention

Earlier engagement and intervention could result in catching and treating David's alcoholism at an initial stage. Interventions to improve his wider health and wellbeing could also be put in place. This may result in preventing longer-term illness and deterioration of his behaviour and relationship with services.

All of the above could result in reduced burden and cost to services, as well as improved health outcomes and quality of life for David.

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**The big picture**

**Systems analysis**

**Lenses on the system**

**Lenses: Key findings**

**The economic case**

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# Annex A: A complex set of parameters

## Socially excluded groups

Social exclusion is a complex concept capturing those:

- With multiple and enduring disadvantage
- Who are cut off from the opportunities most of us take for granted

For the purposes of this project we are starting from a broad definition of what can happen when individuals experience one or more complex problems. While we recognise the limitation of 'grouping' individuals around particular identifiers or needs, we began with a wider lens:

- Asylum seekers and refugees (those with no recourse to public funds)
- Homeless
- Care leavers
- Carers
- People living in remote rural areas
- People with mental health conditions
- People with learning disabilities
- People with physical disabilities
- Substance misusers (alcohol and/or illicit drugs)
- Gypsy, Roma, Travellers
- Ethnic or religious minorities
- Sex Workers
- Non English speaking linguistic minorities
- Men/women suffering domestic violence
- Offenders
- Long Term Unemployed
- Those in severe and persistent poverty
- Migrant workers
- Those in severely deprived neighbourhoods
- Those Not in Education or Training (NEETs) over 18 years
- Older people (particularly those aged 85 years)

N.B. It should be noted that this is not intended as an exhaustive list and does not capture local variation or fluidity between groups

## Primary health care

There are equally complex definitions of primary care:

- Primary care is the term for the health services that play a central role in the local community: GPs, pharmacists, dentists and midwives.
- It can also be considered as the medical care a patient receives upon first contact with the health care system, before referral elsewhere within the system.

The ultimate goal of primary health care is better health for all. The World Health Organisation has identified five key elements to achieving that goal:

- Reducing exclusion and social disparities in health (universal coverage reforms)
- Organizing health services around people's needs and expectations (service delivery reforms)
- Integrating health into all sectors (public policy reforms)
- Pursuing collaborative models of policy dialogue (leadership reforms)
- Increasing stakeholder participation

## Annex B: A shared agenda

Improving the way we meet the primary health care needs of the socially excluded will make a positive contribution to a range of other government priorities

DH	PSA 18: Promote better health and wellbeing for all	DSO 1: Ensure Better Health and Wellbeing for All – empowering people to live independently and tackling health inequalities.	Addressing the health needs of socially excluded groups is key to reducing health inequalities	
	PSA 19: Ensuring better care for all			
HO	PSA 25: Reduce harms caused by drugs and alcohol	DSO 2: Ensure Better Care for All – providing the best possible health and social care, offering safe and effective services where they are needed.		
DCSF	PSA 12: Improve the health and wellbeing of children	Vital signs: access to personalised and effective care; improving health and reducing health inequalities		
	PSA 14: Increase the number of children and young people on the path to success	DSO 1: Help People Feel Secure in their Homes and Communities		
	PSA 9: Halve the number of children in poverty by 2010-11 on the way to eradicating child poverty by 2020	DSO 2: Cut Crime, esp. Violent, Drug and Alcohol Related Crime		
GEO	PSA 15: Address the disadvantage that individuals experience because of their gender, race, disability, age, sexual orientation, religion or belief	DSO 1: Secure the Wellbeing and Health of Children and Young People		Improving health outcomes will contribute to delivery of PSA 16 (people accessing secondary mental health services; moderate to severe learning disabilities; care leavers; offenders under probation supervision)
CO	PSA 16: Increase proportion of socially excluded adults in settled accommodation and education, employment or training	DSO 6: Keep Children and Young People on the Path to Success		
MOJ	PSA 23: Making communities safer (reduce re-offending)	DSO 2: Developing and supporting delivery of the Government's equality strategy		
CLG	PSA 21: Build more cohesive, empowered, active communities	DSO 4: Increasing disabled people's choice and control		
DWP	PSA 8: Maximise employment opportunity for all	DSO 3a: Improve outcomes for most excluded people in society		
	PSA 17: Tackle poverty and promote independence and wellbeing in later life	DSO 3: Protect the Public and Reduce Re-offending		
		DSO 3: To build prosperous communities by improving the economic performance of cities, sub-regions and local areas, promoting regeneration and tackling deprivation		
		DSO 2: Maximise employment opportunity for all		
		DSO 4: Promote independence and wellbeing in later life		
		DSO 5: Promote equality of opportunity for disabled people		

Addressing the health needs of socially excluded groups is key to reducing health inequalities

Improving health outcomes will contribute to delivery of PSA 16 (people accessing secondary mental health services; moderate to severe learning disabilities; care leavers; offenders under probation supervision)

## Annex C: Table of information

A literature review was carried out to support the findings in this evidence pack. This exercise highlighted the lack of available data on the health needs and outcomes of socially excluded groups. It is therefore important that areas and organisations seek to collate and drill down into relevant local information to understand the issues that face disadvantaged groups in their localities. The following table is a summary of some of the sourced information. It is not exhaustive and is intended to highlight some of the types of information that may support a case for further improvements.

Group	Demographics	Health needs and outcomes	Social determinants of health	Primary care usage
Asylum seekers and refugees	UNHCR 2004 data estimated that Britain hosted nearly 300,000 refugees, and in Q1 2009 there were over 8000 applications for asylum in the UK	<ul style="list-style-type: none"> <li>- Basic health needs are broadly similar to those of the host population; however, previous poor access to health care may mean that many conditions have been untreated (Home Office, 2003)</li> <li>- Refugees/asylum seekers can also experience difficulties in expressing health needs due to language difficulties (Burnett and Peel, 2001)</li> <li>- Previous studies show poor health outcomes: one in six refugees has a physical health problem and two thirds have experienced anxiety or depression. (Burnett and Peel, 2001)</li> </ul>	<ul style="list-style-type: none"> <li>- Often a vulnerable population owing to pre and post migration stress often having left conflict areas (Norredam, 2005)</li> <li>- In the UK, asylum seekers can face the effects of poverty and lack of cohesive social support (Burnett and Peel, 2001)</li> <li>- Screening and preventative rather than curative measures may be new concepts to asylum seekers from less developed countries (Rogstad and Dale, 2004)</li> </ul>	<ul style="list-style-type: none"> <li>- Language is a major barrier both to accessing primary care and to reporting health problems (British Medical Association, 2002)</li> <li>- The burden of care can fall on other asylum seekers, refugee communities, faith communities and voluntary organisations (Marmot, 2010)</li> </ul>
Refused asylum seekers (no recourse to public funds)	NAO estimate between 155,000 and 283,500 potentially removable failed asylum applicants in the UK in 2004	<ul style="list-style-type: none"> <li>- Health outcomes similar to asylum seekers (see above) but an increasing body of evidence shows that health deteriorates rapidly and, as refused asylum seekers are not able to claim most benefits, the burden of care is falling on refugee/faith communities and voluntary organisations etc (Marmot, 2010)</li> </ul>	<ul style="list-style-type: none"> <li>- See above</li> </ul>	<ul style="list-style-type: none"> <li>- Many failed asylum seekers may be refused primary care registration owing to a lack of address (Marmot, 2010)</li> </ul>
Homeless (“non-priority” homeless group, as defined in the 1996 Housing Act)	Estimated 40,500 at any one time in England. Predominantly male (90%); highest density in London and outer urban areas (Office of the Chief Analyst, DH 2010)	<ul style="list-style-type: none"> <li>- Homeless people have significantly higher levels of premature mortality and mental and physical ill health than the general population – they are 35 times more likely to commit suicide than the general population and four times likely to die from unnatural causes (Crisis, 1996). See page 32 for more information.</li> </ul>	<ul style="list-style-type: none"> <li>- See page 35 for wider needs</li> </ul>	<ul style="list-style-type: none"> <li>- See page 32 onwards for details of primary care usage</li> </ul>
People with mental health conditions	25-50% of people will experience a mental health condition at some point in their lives (Marmot, 2010). Rates of mental illness are highest in most disadvantaged and marginalised groups in society (Meltzer et al., 2002)	<ul style="list-style-type: none"> <li>- Those with mental health conditions have higher mortality rates (Harris, 2001), higher risk of cardio vascular disease, are three times more likely to be dependent on alcohol, and are more likely to smoke (Social Exclusion Unit Research, 2004)</li> </ul>	<ul style="list-style-type: none"> <li>- High levels of poverty due to low employment and low take up of benefits (Marmot, 2010)</li> <li>- More likely to live in socially deprived areas and poor housing (Marmot, 2010)</li> </ul>	<ul style="list-style-type: none"> <li>- There is also strong evidence that suggests they do not receive appropriate care for physical health problems (Thonicroft, 2006)</li> <li>- 9 of 10 adults with mental health conditions (25% of those severe) receive all their support from primary care (SEU, 2004)</li> </ul>

## Annex C: Table of information

Group	Demographics	Health needs and outcomes	Social determinants of health	Primary care usage
People with learning disabilities	It is estimated that there are 828,000 people over 18 years with a learning disability in England (Department of Health, 2009).	<ul style="list-style-type: none"> <li>- Higher rates of mental health conditions, and respiratory and heart disease (Hollins et al, 1998)</li> <li>- People with learning disabilities are 58 times more likely to die before the age of 50 than the general population (Michael, 2008)</li> <li>- Up to a third of people with learning disabilities have an associated physical disability (Michael, 2008). See page 53 for more information.</li> </ul>	<ul style="list-style-type: none"> <li>- Unemployment rates are high and just 17% of people with mild/moderate learning disabilities and 4% of people with severe learning disabilities who were of working age reported earning more than £100 a week (Emmerson and Hatton, 2008). See page 53 for more information.</li> </ul>	<ul style="list-style-type: none"> <li>- Although people with learning disabilities visit their GP with similar frequency to the general population, they are less likely to receive regular health checks (Kerr et al, 1996).</li> </ul>
People with physical disabilities (the widest definition includes all those with a longstanding illness, disability or infirmity)	The Office for Disability Issues estimates that in 2007/08 there were 10.6 million people with longstanding illness, disability or infirmity.	<ul style="list-style-type: none"> <li>- There is extensive evidence of poorer health outcomes than for non-disabled people (Marmot 2010)</li> <li>- Physical disability has been identified as a cause of depression and is associated with a greater risk of lifetime suicidal ideation (Russell, 2009)</li> </ul>	<ul style="list-style-type: none"> <li>- Higher rates of poverty than the general population. Often have restricted social networks and looser ties to the community. More likely to be victims of bullying and crime than the general population (Marmot, 2010).</li> </ul>	<ul style="list-style-type: none"> <li>- The NHS and its constituent parts are under a legal duty to promote equality of opportunity for disabled people.</li> </ul>
Gypsies and Travellers (all persons with a cultural tradition of nomadism or of living in a caravan and all other persons of a nomadic lifestyle)	Communities and Local Government estimates the community represents 0.6% (c.368,000) of the total UK population.	<ul style="list-style-type: none"> <li>- Studies show poor health outcomes across a range of indicators - see page 42 for further information.</li> </ul>	<ul style="list-style-type: none"> <li>- Often display a sense of fatalism with regard to treatable health conditions and can have low health expectations (SETF Fieldwork, 2009)</li> <li>- Poor site conditions can be a particular problem (Crawley, 2004)</li> <li>- See page 44 for further information.</li> </ul>	<ul style="list-style-type: none"> <li>- Those who are mobile have an increased reliance on A&amp;E and walk in centres which can lead to problems with follow up and continuity of care (SETF Fieldwork, 2009). See page 42 onwards for detailed information.</li> </ul>
Ethno-religious minorities (Black and Minority Ethnic groups captured in the UK census)	It is estimated that BME groups represent 15% of the general population (ONS, cited Tackling the Challenge CQC 2009).	<ul style="list-style-type: none"> <li>- Generally, non-white minorities experience poorer health outcomes, with Bangladeshi and Pakistani minorities having the poorest (Marmot 2010)</li> <li>- High rates diabetes across all non white groups; high rates of heart disease among south Asians; high rates of hypertension and stroke among Caribbean and African groups; high rates of psychotic illness amongst young black men; high rates of STD among Black Caribbean groups (Marmot 2010)</li> </ul>	<ul style="list-style-type: none"> <li>- There is great variation in health outcomes between ethnic groups, generations and gender. Socio-economic inequalities faced by ethnic groups in the UK suggest substantial contribution to ethnic inequalities in health (Marmot 2010).</li> </ul>	<ul style="list-style-type: none"> <li>- All, except Chinese, appear likely to use GP services; Less likely to use hospital services and much less likely to use dental services – evidence on the reasons why is limited (HSE data).</li> </ul>
Sex workers (street and non-street workers, excluding telephone sex)	Approximately 80,000 in the UK (Home Office 2008 from 1999 Europap-UK survey).	<ul style="list-style-type: none"> <li>- Experience a range of poor health outcomes because of the risks associated with their work (see pages 23-28 for detailed information).</li> </ul>	<ul style="list-style-type: none"> <li>- High incidence of violence and rape (Church BMJ 2001)</li> <li>- Poverty and the need to pay for household expenses is often the most cited reason for entering sex work (SETF fieldwork 2009)</li> <li>- Being homeless or living in temporary/insecure accommodation is a common issue for sex workers (SETF fieldwork 2009). See pages 23-28 for information.</li> </ul>	<ul style="list-style-type: none"> <li>- Street sex workers have significantly higher rates of health service use compared to the general population (Jeal 2004)</li> <li>- Sex workers experience a range of psychological and institutional barriers to accessing health care (see pages 23-28 for detailed information)</li> </ul>

## Annex C: Table of information

Group	Demographics	Health needs and outcomes	Social determinants of health	Primary care usage
Non-English speaking linguistic minorities	Of the estimated 5.5 million ethnic minorities in England, 71% are non-English speaking (ONS, 2005).	<ul style="list-style-type: none"> <li>- Broadly similar health needs as asylum seekers/refugees (Ponce et al 2006)</li> <li>- Language barriers may be particularly problematic in mental health care because much mental health diagnosis and treatment relies on direct communication rather than objective tests or medication (Sentell et al 2007 and SETF fieldwork 2009)</li> </ul>	<ul style="list-style-type: none"> <li>- Broadly similar to asylum seekers/refugees</li> </ul>	<ul style="list-style-type: none"> <li>- Language barriers were associated with greater use of diagnostic investigations, lower uptake of preventative services and lower patient satisfaction (Ponce et al 2006)</li> <li>- Less likely to receive appointments for follow-up, less likely to return for follow-up consultations and less likely to comply with prescriptions ((Bischoff et al 2003)</li> </ul>
Men/women suffering violence (any incident or threatening behaviour, violence or abuse between adults who are or have been intimate partners or family members – Home Office 2009))	26% of women and 17% of men experienced at least one incident abuse since 16 (Walby and Allen 2004 from 2001 British Crime Survey). Every year 2 million women experience sexual or domestic violence (DH Commissioning 2010)	<ul style="list-style-type: none"> <li>- People who report being in poor health, having a long-term limiting illness or disability are disproportionately more likely to have experienced abuse in the past (Finney, BCS 2004/5)</li> <li>- Associated with higher rates of mortality. 2 women per week are likely to be killed by a current or former partner (Home Office, Crime Reduction website 2009)</li> <li>- Women living with domestic violence are 3.8 times more likely to suffer depression than those who are not (Golding 1999)</li> <li>- Domestic violence is a common method of exposure to HIV ((DH 2000)</li> <li>- Women experiencing domestic violence are 15 times more likely to misuse alcohol and 9 times more likely to misuse other drugs than women in the general population (Start et al., 1996)</li> </ul>	<ul style="list-style-type: none"> <li>- Estimates from 2003 report that domestic violence accounts for 16% homelessness acceptances (Women and Equality Unit 2003)</li> </ul>	<ul style="list-style-type: none"> <li>- The longer term negative health consequences are associated with high use of health services (Campbell 2002)</li> </ul>
Offenders	In June 2009 the prison population was 83,500 (95% male; 5% female) (MOJ Prison Population Stats 2009)	<ul style="list-style-type: none"> <li>- Higher rates of HIV and hepatitis infection than the general population (Reducing Reoffending SEU 2002)</li> <li>- A study in England and Wales showed that male offenders under the criminal justice community supervision were at least 10 times more likely to die by suicide than men in the general population (cited in Pratt et al., 2006)</li> <li>- in many cases, high levels of mental health (SETF analysis of OASys 2005/2006)</li> </ul>	<ul style="list-style-type: none"> <li>- 55% of women offenders and 53% male offenders identified unemployment and skills as an issue contributing to their offending (reducing reoffending SEU 2002)</li> </ul>	<ul style="list-style-type: none"> <li>- Evidence of under-use of primary care services: on admission to prison 40% of prisoners deny contact with a GP and on release, 50% of prisoners are not registered a GP (NEPHO 2005 and SEU 2002)</li> </ul>
Unemployed (including long-term unemployed, those on incapacity benefit and low-skilled workers)	February 2010 ONS statistics reported 2.46 million unemployed	<ul style="list-style-type: none"> <li>- Unemployed people report increased rates of limiting long-term illness, mental illness and cardiovascular disease (Bartley and Plewis 2002; Thomas 2005)</li> <li>- Prolonged unemployment associated with a raised risk of smoking and problem drinking, and symptoms of anxiety and depression (Wadsworth et al., 1999)</li> </ul>	<ul style="list-style-type: none"> <li>- Families without a working member are more likely to suffer persistent low income and poverty. There is also evidence of a correlation between lower parental income and poor health in children (DH Dame Carol Black)</li> </ul>	<ul style="list-style-type: none"> <li>- Cross-sectional studies and factory-closure studies have documented higher levels of hospital admissions, doctor visits and outpatient visits amongst unemployed (Mathers and Schofield 1998)</li> </ul>

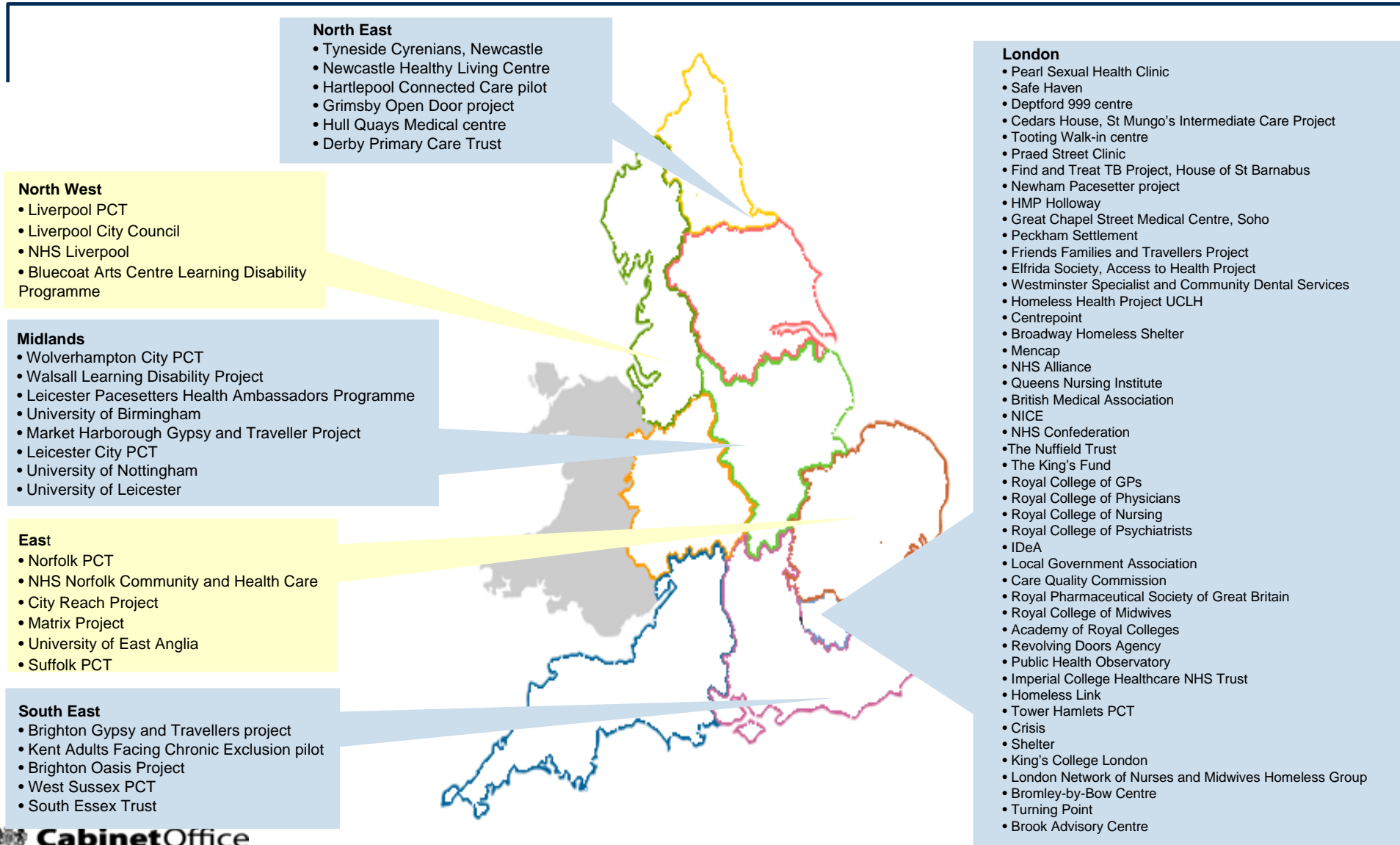


## Annex C: Table of information

Group	Demographics	Health needs and outcomes	Social determinants of health	Primary care usage
Those in severe and persistent poverty (persistent low income – at least 3 out of 4 years at below 60% median income)	Figures from 2003-2006 record that 9% of individuals experience low income for at least 3 years (HBAI, 2007/08). Women are more likely than men to be included in this group; disabled people more likely than those with no disability; and individuals headed by a member of an ethnic minority also more at risk of living in low-income households (HBAI, 2007/08)	<ul style="list-style-type: none"> <li>- Two fifths of 45-64 year olds on below average income have a long term limiting illness or disability which is twice the rate of those on above average income (GHS – average of three years up to 2008).</li> <li>- The latest available data found that men aged 25 to 64 from routine or manual backgrounds were twice as likely to die as those from managerial or professional backgrounds (Benezeval, 2001)</li> <li>- 22% of men and 24% of women in the poorest quintile suffer mental problems compared with 9% and 16% of those on average incomes (www.poverty.org)</li> </ul>	- Lack of money restricts access to the fundamental conditions of health, such as adequate housing, good nutrition and opportunities to participate in society (McDonough et al, 2005)	- Lack of available information
Migrant workers (A2s and A8s – individuals from accession countries from central and eastern Europe)	According to the February 2010 Labour Market Statistics, there are 3.72 million non-UK born people in employment	- Migrants from accession countries are typically young and healthy on arrival (LGA, 2007)	- Migrant workers can often live in overcrowded accommodation which could increase the risk of diseases, such as tuberculosis (HPA, 2008)	- Reports of inappropriate use of emergency services. Increasing reports of late use of maternity services, making planning difficult (LGA, 2007)
NEETS (not in employment, education or training, aged 18-24yrs)	Quarterly statistics from November 2009 show 933,000 18-24 NEETs (DCSF, 2009)	<ul style="list-style-type: none"> <li>- Over a quarter of 18–24 year olds are NEET because they are pregnant or looking after their children, and one in ten because of disability or illness (DCSF, 2009)</li> <li>- Increased use of illicit drugs and increased probability of smoking has been reported among the long-term unemployed (Hammerstrom, 1994)</li> </ul>	- Strong predictors of later life NEET status include family's socioeconomic background, parental education and area of residence (Robson, 2008)	- Lack of available information
Older old people, particularly those aged 85+ years	ONS 2007 figures show that 4.5% (nearly 3 million) of the total population is 80+. Currently only 1.1% (13 000) of people 85+ are from ethnic minority groups (using 2001 census). The population of older old is expected to grow as populations are living longer (Ageing Strategy, 2009)	<ul style="list-style-type: none"> <li>- Health outcomes have been improving for older people e.g. life expectancy is at its highest. However, evidence shows that people are spending more years in poorer health (National Service Framework, DH)</li> <li>- 700,000 older people are currently affected by dementia. This is projected to double over the next 30 years (Dementia Strategy, DH, 2009)</li> </ul>	- People aged 75+ in the poorest wealth quintile are at almost twice the risk of mortality compared with those in the richest quintile (ELSA, Wave 3, 2008)	- Nearly 30% of those aged 80+ report having the greatest difficulty in accessing basic services such as GPs and dentists (ELSA, Wave 1, 2006)
Those in severely deprived neighbourhoods	61 Working Neighbourhood Fund areas	<ul style="list-style-type: none"> <li>- The difference in life expectancy between the local authority districts reporting the highest and lowest life expectancies is 8.5 years for men and 6.8 years for women – with a tendency for the highest mortality rates to be located in urban and declining industrial areas (Wanless, 2003)</li> <li>- Women in the most deprived wards on average expect poor health 13.6 years earlier than their counterparts in the least deprived wards (PSC, 2009)</li> </ul>	- No clear information available	- Lack of available information

# Annex D: Fieldwork

The project team is hugely grateful to all of the individuals, institutions and organisations who contributed to the project



## Annex D: Methodology overview

**Four 'Lenses' to stress test the system** – selected four groups to provide a horizontal lens 'across' social exclusion and;

- Collate and evaluate emerging practice
- Showcase innovation in 'models' of care
- Evidence specific issues around access and quality of care

**Partnered with 2 geographical areas** – deep dive into the system to gather evidence on issues and solutions around:

- Workforce capability and development
- System barriers and incentives
- Strengths and weaknesses of primary care in action
- Cost benefit - needs assessment, allocative efficiencies, operational efficiencies
- Strategic planning and commissioning
- Partnership working

**Roundtable events** – to build support and tap into expertise in the field

- Royal College of GPs
- Academic and expert practitioners roundtable
- Nursing practitioners' workshop
- Commissioners' roundtable
- Providers' workshop
- Oral health and pharmacy

**Primary and secondary analysis** – to generate a detailed picture of where we are and provide a robust evidence base

- Analysis 'grid' to bring together data and research across all of the groups on health outcomes and primary care needs
- Second phase of more detailed analysis on demographics, needs and outcomes of four lens groups
- Call for evidence to over 100 organisations
- Policy mapping
- Literature review
- International research to highlight innovation and identify promising practice

**Communities of practice** – to generate momentum for change and draw on frontline knowledge on issues and solutions

- SETF PSA 16 community of practice
- Mediated nurse forum web-chat - QNI
- IDeA Healthier Communities

**Qualitative research** – to gather client and practitioner perspectives

- Customer journey mapping with sex workers, homeless, people with learning disabilities and Gypsy, Roma, Traveller clients
- Focus group sessions
- Case studies

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5	(1) Life expectancy statistics (OECD, 2009) (2-4) <i>NHS 2010-2015: From good to great. Preventative, people-centred, productive</i> (NHS, 2009) (5) Average inpatient waiting times (NHS, 2009) (6-9) <i>NHS 2010-2015: From good to great. Preventative, people-centred, productive</i> (NHS, 2009)
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