inclusion
health

Hidden Needs

Identifying Key Vulnerable Groups in Data Collections:

Vulnerable Migrants, Gypsies and Travellers, Homeless People, and Sex Workers

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Foreword

Our report, *Hidden Needs,* is about making the invisible visible. It demonstrates the yawning gaps in data, information analysis and research in four of the most vulnerable populations in society. If we are to make real inroads into improving the health of the poorest fastest, then we must first create the tools for measuring the inequity reliably now and over time. We also need to provide *local* as well as national intelligence to support health and wellbeing strategies, commissioners, providers, and communities.

Hidden Needs was commissioned and overseen by the Data and Research Working Group of the Inclusion Health programme and approved for publication by the National Inclusion Health Board. It is one of a series of reports from the Inclusion Health programme. It identifies the gaps in information and data where the burdens of ill health and untimely death are greatest for each of the groups. It also highlights areas where good data is already collected but barely used.

It is clear that the actions recommended cannot be achieved by one agency alone. Together they represent a test of whether the newly reformed health system can respond to some of the greatest and largely invisible injustices in our society.

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EXECUTIVE SUMMARY

Statement of Intent

The four vulnerable and excluded groups prioritised by the Inclusion Health Board experience some of the poorest health outcomes in England. They form the focus of this report and comprise

- **vulnerable migrants**
- **Gypsies and Travellers**
- **homeless people**
- **sex workers**.

Amongst **asylum seekers and refugees**, mental health problems include post-traumatic stress disorder (PTSD), anxiety, depression and phobias, with rates up to 5 times higher than in the general population. There is evidence of late booking, poor antenatal care and poor pregnancy outcomes. **Gypsies/Travellers** have low rates of GP registration, poorer general health and high rates of limiting long term illness, substantially elevated smoking rates, poor birth outcomes and maternal health, and low child immunisation rates and commensurate elevated rates of measles, whooping cough, and other infections. **Single homeless people** are five times more likely to use Accident & Emergency Services than the general public and 3.2 times more likely to have hospital admissions. Early onset of drug misuse, severity of alcohol use, and drug/alcohol dependency are major problems. Poor mental health is frequently reported, including depression and other affective disorders, anxiety states, personality disorder, and schizophrenia. **Sex work** carries a high risk of sexually transmitted infections (STIs) and blood-borne viruses (BBVs) for the sex worker & also for the client. 85% of street sex workers report using heroin and 87% using crack cocaine. Many sex workers have poor mental health, relating to a complex set of factors including their childhood, use of drugs, and social circumstances (including homelessness).

Yet it is difficult to obtain a comprehensive national or local level picture of these health needs because of the lack of capture of these groups in standardised datasets for measuring and monitoring access to health care and in denominator datasets. The purpose of information is to highlight the extent of unmet health need in these vulnerable groups and to drive service development to meet these needs. In order to inform service development we need much better, more granular information on the range of the *particular* health needs of these groups obtained from detailed analyses and surveys as well as an ability to monitor trends in key indicators at local and national level. We also need to be able to understand the extent and range of service provision for these groups. This report aims to describe existing data sources and how better information can be collected, analysed, and reported in order to inform commissioning and service development.

The approach adopted in this report has been initially to review trigger- and group-based approaches to defining vulnerability and vulnerable groups. The report recognises that triggers of vulnerability are contingent and complex and that there are no necessary or sufficient causes for people to become vulnerable. The causal role of risk factors (acting singly or in combination) is still poorly understood, especially their interaction with individual (protective) and wider social factors. Longitudinal prospective cohort studies are needed as the major contributor to causal analysis.

In order to focus on data availability and gaps an attempt has been made for each of the four vulnerable groups to:

- delineate a spectrum of vulnerability in order to identify the most vulnerable subgroups;
- within the most vulnerable subgroups to identify the main burdens of morbidity and mortality to provide a focus on areas where data capture will be most important and where gaps should be prioritised.

A 'spectrum of vulnerability' approach was adopted for several reasons. Data on processes of vulnerability and exclusion are poor, especially at local authority level. The rationale for a group-level approach lies in the shared experiences of group identity, risk exposures, discrimination, marginalization, disadvantage, value systems, distinctive history, etc. The approach has utility when the group/category definition captures vulnerability with high sensitivity and high specificity (e.g. Gypsies/ Travellers). When the group/category definition captures vulnerability with high sensitivity but poor specificity (e.g. migrants), defining vulnerability at sub-group level provides specificity.

The report then identifies health inclusion issues for each of the four groups. All experience adverse socio-economic and environmental circumstances; marginalisation and discrimination; unfavourable lifestyle circumstances; and inadequate access to good quality health services. Additionally, some issues are specific to each group, e.g. post-flight health deficits for asylum seekers/refugees; poor/insecure site accommodation for Gypsies/Irish Travellers, etc.

Findings

Chapter 3 identifies a spectrum of vulnerability for each of the four specified groups. For example, vulnerable migrant subgroups include: failed asylum seekers / no recourse to public funds migrants; asylum-seekers suffering depression, anxiety, and post-traumatic stress disorder; trafficked and undocumented migrants; asylum-seeking children, including those who are unaccompanied; rough-sleeping A10 migrants, some of whom have weaker welfare protection; and migrants with acute/chronic illness, for example, sub-Saharan migrants with HIV/AIDS.

Chapter 4 addresses health inclusion issues for each of the four groups. Those for Gypsies/Irish Travellers, for example, include: the burden of non-fatal disabling conditions, the cumulative effect of adverse living circumstances; the burden of premature mortality, including infant mortality, maternal mortality, and suicide; a major gap in life expectancy but even wider gap in health expectancy (healthy life expectancy & disability-free life expectancy); diabetes, smoking, physical inactivity, arthritis and back conditions; communicable diseases and low immunisation rates; poor access to primary and secondary health care services; and health issues around poor rights to a home (especially lack of or insecure site provision and poor amenity provision).

Chapters 5, 6, 7, and 8 investigate denominator data, routine data availability, and data gaps for each of the four vulnerable groups.

Chapter 5 addresses data availability and gaps for *asylum seekers, refugees, and other vulnerable migrants*. Denominator data on migrants is available from the 2011 Census, NHS Flag 4 records, and birth and death registrations and multiple sources of data are available on migrant subgroups but with poor capture of refugees, failed asylum seekers who remain in the country, other overstayers, and undocumented migrants. There is poor capture of the use of primary and secondary health services by asylum seekers and refugees (but country of birth is usual in primary care but not hospital datasets); poor capture of asylum seekers in mental health services (except children and adolescents); good capture of children in need and looked after children,

and reasonable capture of migrants in communicable disease datasets. Only country of birth is captured in a limited set of health surveys.

Chapter 6 looks at data availability and gaps for *Gypsies and Travellers*. Denominator data is available from the 2011 Census but currently there has been no adoption of the classification in health datasets and limited adoption in social care and wider datasets. There is poor capture of the use by these groups of primary care services, though Read Codes are available, but no capture in hospital datasets. There is no capture of Gypsies and Travellers in sources on birth outcomes and poor or no capture in sources on maternal morbidity and mortality (UKOSS, HES, CEMCH). The Maternity Services Secondary Uses Dataset may be of utility once data accrue. Capture on immunisation datasets (COVER, KC50) and infectious disease notifications is very poor or non-existent, and data coded to Gypsy/Irish Traveller on other datasets, such as the Millennium Cohort Study, is almost entirely absent. There is, however, good capture on community health services datasets (Referrals, Assessments, and Packages of Care) and for children looked after. Capture is also good for some of the determinants of health, notably, education and accommodation needs. Options for the capture of Gypsies/Irish Travellers in health datasets include: the use of Child Death Overview Panel data, postcode data for official sites, the use of distinctive Gypsy/Irish Traveller names to identify community members on datasets, and health survey data (the Integrated Household Survey pooled data once surveys accrue). In addition around 330 Gypsies/Irish Travellers are captured in the 2012 GP Patient Survey (albeit registered with a GP in England).

Chapter 7 addresses data availability and gaps in the 'single homeless' or 'non-statutory homeless' population. Denominator data on the homeless population (rough sleepers and those in hostels) is available from the 2011 Census, though with need for quality assessment, and that for rough sleepers from the official rough sleeper counts, though both are counts at one point in time. The only coding for homeless people in data on the use of hospital services (the HES dataset) is for 'no fixed abode' or postcode ZZ99 3VZ. There is good capture on use of alcohol and drug treatment services (NATMS and NDTMS) but poor or no capture on the use of mental health services (except via HES). The 'no fixed abode' postcode is collected on the Mental Health Minimum Data Set (MHMDS) but does not flow to commissioners.

Alternative sources to these routine datasets include Supporting People data (but available for primary client group only - so no data is available on dual diagnosis – and episode- rather than person-based; moreover, central reporting of the data has now ended), the CHAIN database in London (which includes health support needs), and the computerised records of specialist practices.

Chapter 8 addresses data availability and gaps in the sex worker population. Denominator data is poor, the only estimates that are available being those based on multipliers drawn from records of specialist and other services. Options include capture-recapture methods, though multiple sources that uniquely identify sex workers are unlikely to be available. There is no capture in primary care and hospital data (though sex worker Read Codes have recently been added). There is capture of sex workers in the genitourinary medicine clinic activity dataset & the HARS dataset (AIDS/HIV) but 'sex worker' coding was recently removed from the drug treatment services dataset (NDTMS). There is no capture in mental health services and poor capture of physical violence/assault and sexual abuse.

Chapter 9 examines methodologies for developing community asset mapping processes, making reference to contributions by bodies such as the Young Foundation and IdeA. Although much of this work on measurement is still at an early stage of development, the 'enhanced' JSNA requires health and wellbeing boards to consider what local communities can offer in terms of assets and resources to help meet identified needs, to be incorporated into the narrative on JSNA evidence.

Conclusions

- There is no clear data strategy for vulnerable groups and a case for one to be produced *[with PHE and NHS England responsibilities]*
- Collection and reporting is not standardised across datasets/government departments
- There is a surprising amount of data that is underused though little is currently known about its quality
- A strategy with clear implementation objectives is achievable and would support the localism and inequalities agendas

- Significant early progress could be made through partnership between *PHE, NHS England, OGDs , HSCIC and the Third Sector*
- Longer-term progress could be made by working with research funders to fill gaps identified

Recommendations for Improved Data Capture of the Four Vulnerable Groups

These recommendations are divided into: data collection/reporting actions; analyses of existing data actions; filling research/methods gaps actions; and longer-term actions (with an indication in parentheses […] of the organisation(s) responsible for making the changes).

1. *Data collection/reporting*

   To the Health and Social Care Information Centre (HSCIC)

   - The ethnic category codes currently used in the NHS Data Dictionary and the Commissioning Data Set Flows are those in the classification used for the 2001 England and Wales Census. Unlike in 2001, there has been no Data Set Change Notice mandating the adoption of the 2011 Census ethnic group classification (which includes 'Gypsy or Irish Traveller'). *The adoption of the 2011 Census ethnic category classification* in the NHS Data Dictionary would propagate the 2011 classification across all current NHS ethnicity data collections. This would have a transformative effect on the capture of Gypsies/Irish Travellers in routine data collection, including in those areas where there is strong evidence that Gypsies/Travellers are strongly disadvantaged. ISD Scotland has adopted the 2011 classification in the Scotland Data Dictionary.

   - Harmonise a more detailed coding for housing status across routine datasets that would replace 'no fixed abode', differentiating groups such as 'sleeping rough', 'sleeping in a hostel', and 'in insecure or short-term accommodation,

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such as in a squat or on a friend's floor' to align with the Department of Health's definition of vulnerable homeless people [Cross-government/HSCIC]. Some further thought may need to be given to the exact definition to align to so as to ensure that there is agreement on its uniform use. Replace current 'no fixed abode' coding on HES (Admitted Patient, Outpatient, & A & E) Datasets with such coding and introduce on all relevant variables (e.g. 'Source of Admission', 'Destination on Discharge', 'Attendance Disposal', etc.).

- Identify no fixed abode postcode (currently collected) in Mental Health Minimum Data Set commissioner extracts: these have never flowed in MHMDS so an additional data item is needed for future versions of the dataset.

To Public Health England (PHE)

- Replace the open response 'ethnicity' field for the index case on the HPA disease notification form template with 2011 Census ethnic group classification (to capture Gypsies/Irish Travellers).
- Add 'sex worker' coding to National Drug Treatment Monitoring System's Core Dataset.
- Add a data field on ethnic group (2011 classification) to that collected on childhood immunisation coverage at ages 1, 2 and 5 through the *Cover of Vaccination Evaluated Rapidly (COVER) data collection*. As the source of this information is Child Health Information Systems (CHISs), it should be possible to source ethnicity from NHS birth notification records so long as the 2011 classification is adopted.

To statutory and third sector organisations working together

- *The commissioning of specialist surveys* may, in the longer term, provide the most comprehensive solution to current poor data coverage. The case for such surveys needs to be made collectively by the organisations needing to use the findings. There has already been a longitudinal survey of new refugees conducted by the Home Office and a specialist survey on the multiply

excluded homeless people. The two groups with poorest coverage in datasets are Gypsies/Irish Travellers and sex workers. The All Ireland Traveller Health Study (AITHS) provides an exemplar approach to obtaining baseline data on the wider health and well-being of the Gypsy/Traveller population. If a survey(s) was to provide data for upper tier local authorities, use of 2011 Census data could provide a sampling frame. There have been a few specialist surveys of sex workers conducted in the USA and Australia: it is likely that development work would be needed to identify methodological approaches that would maximise capture and minimise non-response. *[PHE/HSCIC/Third Sector bodies]*

▪ Working with umbrella membership bodies for organisations and individuals working with people in the four vulnerable groups, support development of sampling frames for special cross-sectional surveys operationalizing these through their membership. These surveys would use consistent methodologies across groups and collect data that is comparable to major government health and social surveys, such as the Health Survey for England. *[Third Sector bodies, HSCIC, PHE]*

2. *Analyses of existing data*

For the following analyses to become routinely available, a case would need to be made by PHE and with other key partners and respective responsibilities for data access/analysis/interpretation agreed in the context of information governance requirements.

▪ Provide analyses of Gypsy/Irish Traveller postcodes (available for authorised sites) in datasets for JSNAs *[Public Health England and partners]*

▪ Provide analyses of postcoded data (no fixed abode and hostel population) for vulnerable homeless populations nationally and to assist local JSNAs (examples of good practice include mortality research using Homeless Link's Homeless UK Database) *[Public Health England with Homeless Link* providing the list of hostels from Homeless UK via postcodes]

▪ Commission table sets from the 2011 Census (where not part of standard table outputs) for upper tier authorities (where feasible) that would provide data for JSNAs on the health and socio-economic position of the homeless, Gypsies/Irish Travellers, and migrants (no information is available on sex

workers), e.g. age standardised LLTI/not good health rates/ratios, and make such table sets publicly available. *[PHE]*

- Add an indicator at trust level to the NHS Outcomes Framework on 30-day readmission after discharge for the 'no fixed abode' population *[NHS England]*

- Scope and (if feasible) measure "did not attend" (DNA) rates in outpatient settings and left without being seen rates in accident and emergency (A & E) for the 'no fixed abode' population as an indicator of how hard to reach services are *[HSCIC].*

- Exploit opportunities for data linkage (e.g. CHAIN [Combined Homelessness and Information Network] database records and HES), building on current discussions on standardisation of housing need measures *[Research funders and key partners]*

- Investigate utility of existing recording systems (like INFORM) used by homelessness service providers/agencies

- Bring together such data and analyses for the four vulnerable groups as part of an Annual Progress Report on Inclusion Health as a major step in addressing health inequalities. It is not justifiable to request enhancements in the data that is collected without transparent enhancements in its analysis *[PHE,NHS England]*

3. *Longer Term changes: Filling Research Gaps*

- Work with research funders (to encourage themed calls for research addressing gaps in health needs of the 4 vulnerable groups) *[Data and Research Working Group, Inclusion Health Board, research funders]*

- Add value to existing surveys of vulnerable homeless service users (for example, Homeless Health Needs Audit Tool) through standardisation and use of Health Survey for England questions *[HSCIC/Homeless Link/research funders]*

- More comprehensive assessment of sex workers' numbers/needs: draw from US and Australian survey methods *[Research funders]*

- Commission a methodology for estimation of the size of the four vulnerable groups at upper tier local authority level *[NHS England/PHE/researchers]*

- Consider adding ethnic group to the information collected on the immunisation of children aged 13-18 years on *the KC50 return* from Trusts providing immunisation services. *[PHE]*

- Identify which *specialist PMS practices* provide primary care services for any of the four vulnerable groups and investigate the scope for the central reporting of data. *[HSCIC; NHS England; CQC].*

- Pilot the feasibility of rolling out the CHAIN database model to major urban areas outside London to improve capture of rough sleepers/other vulnerable homeless people could be piloted *[research funders]*

- Asset mapping: track the work of IDeA, Young Foundation, *et al*. on *asset mapping, asset driven approaches to the commissioning cycle, and measurement of local well-being* with a view to making recommendations for JSNA data collection. *[research funders]*

1.   INTRODUCTION: THE POLICY CONTEXT

Within the broad strategy to tackle health inequalities, the Inclusion Health programme - led by the National Inclusion Health Board - aims to improve access to health services and outcomes for the most vulnerable people. An initial list of four groups has been prioritised, namely, vulnerable migrants, Gypsies and Travellers, homeless people, and sex workers.

Under the health system reforms, local authorities will establish a health & well-being board & undertake a joint strategic needs assessment (JSNA). The JSNA will be used to prepare the joint health and well-being strategy, which in turn will inform clinical commissioning groups and the local authority commissioning plans. The health and well-being board will be a key forum to consider service integration across NHS services, health-related services provided by the local authority, and other local providers, e.g. voluntary and community sector.

This set of projects on health inclusion, of which a focus on inclusion in data sources is one, is now being undertaken to identify what more must be done to include the needs of these groups in the commissioning of health services. The groups have been identified as amongst the most 'vulnerable' and socially excluded. Two key dimensions of exclusion have been identified: (i) The difficulty these groups experience in accessing health services generally and primary care in particular and the need to address prejudice, cultural and practical barriers faced by vulnerable people when accessing health services; (ii) that these groups suffer multiple and enduring disadvantage, their health outcomes being amongst the worst of any groups: they are thus deprived of the opportunities available to the wider society and face discrimination and significant health inequalities.

To improve their position the Health Inclusion Board has commissioned work to identify gaps in data collection and to look to identify the specific interventions that produce positive health outcomes to ensure that the needs of these vulnerable groups are better reflected in JSNAs. This will also encompass a focus on the life-course and the wider determinants of health. With respect to Gypsies and Travellers the Board / Ministerial Working Group have suggested an initial focus on childhood immunisations, maternal health, and infant mortality. The Department of Health has expressed a commitment to work with the National Inclusion Health Board to improve the evidence base on the health of homeless people and the recording of homeless persons in the health system[1]. The new Public Health Outcomes Framework (which sets out the desired outcomes for public health & how these will be measured) includes two indicators on homelessness but these relate only to statutory homelessness and a concern has been expressed that they do not encompass rough sleepers/those in hostels or issues around hospital discharge arrangements. A ministerial working group on homelessness has been established that brings together eight government departments to tackle the complex causes of homelessness, implicating health, housing and

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[1] Department for Communities & Local Government. *Making every contact count: a joint approach to preventing homelessness*. London: DCLG, 2012 (August). HM Government. *Vision to end rough sleeping: No Second Night Out nationwide*. London: Department for Communities and Local Government, 2011 (July).

work issues. A report by the ministerial working group setting out government commitments on preventing and tackling homelessness has been published: *Making Every Contact Count: A joint approach to preventing homelessness*. This follows an earlier report on *Ending rough sleeping: No second night out nationwide*. Accurate data is also needed on the sex worker population and vulnerable migrants for the planning and targeting of services and other action.

As they are socially excluded, all four groups are often not picked up in traditional data sources and surveys. Small numbers can make them easy to ignore and they often fall between categories or are rendered invisible in residual 'other' groups. They may also be poorly reported in current national data sets because of their transient lifestyle and their multiple complex problems. Lack of inclusion in primary care may lead to invisibility in the health care system as a whole.

Key policy approaches that feed into this programme of work include:

Reduction of health inequalities:

Health and Wellbeing strategies are expected to encompass issues that are wider than health services alone and there is a legislative duty on NHS organisations to tackle inequalities in access and health outcomes. Tackling inequalities in health are at the heart of the Government's health reforms. The National Health Service Commissioning Board and clinical commissioning groups will be under legal duties to have regard to the need to reduce inequalities in access to and outcomes from health services.

Localism:

The coalition's policy focus on localism is aiming to give more freedoms and flexibilities to local authorities to address the needs of these vulnerable groups.

Public Health Outcomes Framework:

Recent developments in data collection have informed the development of the public health outcomes framework.

There is also an intersection with international work, notably: the WHO review of social determinants and the health divide, led by the Institute of Health Equity, and the WHO project on the identification of targets and indicators, based on a social determinants of health measurement framework, to monitor progress on addressing the level and distribution of non-communicable diseases in high, middle and low income countries across the world.

The concepts of vulnerability

The concept of 'vulnerable groups' and the 'vulnerability' of populations is contested. In a health context it is largely an imposed category, linked to processes of exclusion, rather than a group identity, and the people thus labelled may challenge it or decline to accept it.

Definitions of the term vary. Some emphasise the emotional dimension of vulnerability, e.g., 'vulnerability is generally held to refer to those individuals or groups who, due to age, ill-health, infirmity, minority status or their otherwise disempowered position in society may be open to exploitation (whether physical, emotional or psychological)'. The literature indicates that those in vulnerable groups are more likely to have multiple vulnerabilities than discrete vulnerabilities. Others use the concept of vulnerable groups as a synonym for disadvantaged groups or socially/economically excluded groups.

Indeed, there is substantial overlap in the terms used to describe these groups. The policy literature also variously describes them as 'disadvantaged', 'marginalised', and 'socially excluded' groups. However, most reports emphasise the complexity of needs underlying these groups whatever label is used to describe them. Some of these groups have also been described as 'hidden populations'. Sex work, for example, by its nature is frequently conducted clandestinely or covertly, not least because of the stigma attaching to this work. There are also legal issues associated with sex work (including soliciting, loitering, call-girl cards, owning or working in a brothel, and kerb crawling). In other cases, the associations of sex work with organised crime, including drug dealing and trafficking, may render it invisible. Trafficked women and young people may be an especially hidden sector. Sex work may also be a transient occupation making it difficult to track for healthcare purposes. Furthermore, studies use the concepts of both 'vulnerable individuals' and of 'vulnerable categories or groups' where vulnerability is related to group membership. These two types of vulnerability may be mutually implicated in each other.

2. TRIGGERS AND GROUP-BASED APPROACHES

There are clearly a number of approaches to addressing vulnerability in the four identified groups (other groups have been included in a longer list prepared by the Inclusion Health Board), including: (i) Identification of the triggers of vulnerability; (ii) Addressing vulnerability as a group- or sub-group based phenomenon.

An understanding of triggers and pathways (or use of sequence analysis) is important to an understanding of how people reach the states of homelessness and sex working or become vulnerable as Gypsies/Travellers and asylum seekers/refugees. The pathway process is somewhat more visible in the case of vulnerable migrants such as failed asylum seekers and more firmly rooted in group-based characteristics in the case of Gypsies and Travellers. Knowing what propels people into these states and what may protect them from entering them is essential to preventative health measures and the avoidance of recurrence. Indeed, in the case of homelessness, there has been a strong focus on prevention as well as the care of these who become homeless (for example, a toolkit has been prepared to help prevent rough sleeping, the prOMPT toolkit, and there is some data collection)[2]. With regard to this group, there may also be complex intersections with the housing market, more particularly the supply of affordable housing, and with welfare protection and support services. Indeed, macro-economic factors may also be important, the current and recent recessions having affected the housing market in different and quite specific ways.

One of the difficulties of undertaking studies in this area to inform JSNA work is the sheer complexities surrounding the issue of triggers, that is: what is a cause of, say, entering homelessness or sex work and what is a consequence. These webs of causal and consequential factors are extremely difficult to unravel with respect to establishing the direction of causation. For example, ill health, drug and alcohol misuse, and mental illness can be a cause of homelessness or can develop or be exacerbated as a result of homelessness. Studies have begun to explore this area by looking at the covariate factors and a long list has been assembled. Particularly influential has been the work of Susan Fitzpatrick and colleagues at Heriot-Watt University, based on their 'Multiple Exclusion Homeless Across the UK' survey (a multistage quantitative survey conducted in Belfast, Birmingham, Bristol, Cardiff, Glasgow, Leeds and Westminster). This study shows consistent evidence of a higher incidence of difficulties during childhood amongst homeless people. Most of the multiply excluded rough sleepers investigated had experienced troubled childhoods (school and/or family problems, traumatic experiences like physical or sexual abuse, and homelessness and neglect). For example, 36% of the multiple exclusion homeless had been suspended, excluded, or expelled from school, 24% had parents or step-parents or carers with a drug or alcohol problem, and 21% had been brought up in a workless household. A Department of Communities and Local Government study of 16/17 year olds accepted by a local authority as homeless found that 54% had been excluded from school, 44% had parents who had suffered

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[2] DCLG publishes homelessness prevention statistics (notably potentially homeless households being helped to access a private tenancy).

from mental health problems, and 17% had experienced sexual abuse. Breakdown of family relationships (including parental separation and divorce) is another important key trigger of youth homelessness. Fitzpatrick *et al*. document the median age of first occurrence of 13 common experiences amongst the multiple exclusion homeless: some occur with high frequency, e.g. involved in street drinking 53% (median age 18); was a victim of violent crime (including domestic violence),43% (median age 20).

Most of these factors preceded homelessness or were antecedents of it but the percentages reveal that not all of the multiply excluded homeless experienced these factors and in some cases particular factors were compounded by the existence of several others. Because of their frequency, they can be regarded as risk markers (and they differ from the covariates for families who are rehoused following acceptance as statutory homeless) but may have poor predictive value as single measures. However, what we do not have data for is people who had the same risk markers (again perhaps compounded by the presence of other sets of factors) who did not become homeless, people who were protected from becoming homeless through personal resilience, their own network of family and friends, and other forms of social protection. Ideally, large longitudinal datasets / cohort studies are needed to identify causal pathways.

The literature on homeless persons and other vulnerable groups and on what causes vulnerability suggests that concepts of *necessary* causes (i.e. the vulnerability cannot occur unless it is present) and of *sufficient* causes (that it inevitably leads to vulnerability) may not be relevant. Again, the work of Fitzpatrick and colleagues on homelessness points to a much more complex picture. Fitzpatrick employs what she terms a 'critical realist' approach to develop a more sophisticated theory of social causation as *contingent*: 'Given the open nature of social systems, something may have a 'tendency' to cause homelessness without 'actually' causing it on every occasion, because other (contextual) factors may often – or even always – intervene to prevent correspondence between cause and effect'[3]. The contextual factors may include 'buffer' factors like targeted prevention policies or protective ('anchor') social relationships that stop people falling off track and entering a problematic way of life. Secondly, critical realist explanations are *complex:* they frequently involve multiple causal mechanisms which are inter-related or intersect. Thus, with the different types/groups of vulnerability, one has to allow for the possibility of a range of quite separate causal routes into the same experience. Fitzpatrick puts it thus: 'Constellations of inter-related causal factors are likely to 'explain' homelessness in any particular case, and the challenge is to identify common patterns that can be explained by the "qualitative nature' of recurring antecedents – i.e. *what it is about* these factors that could *tend* to cause homelessness'.

An example is poverty: the key question for a critical realist is not *what proportion of poor people are homeless*? But rather *what is it about poverty that could cause homelessness*? Poverty is not a necessary condition of vulnerability. For example, most people living in poverty do not experience homelessness and homelessness is found amongst those who are

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[3] Fitzpatrick S. Explaining homelessness: a critical realist perspective. *Housing, Theory and Society* 2005; 22(1): 1-17.

not poor. As Fitzpatrick points out, homelessness occurs in areas of the UK where access to affordable housing is less problematic and amongst groups for whom priority is given in social housing.

With respect to homelessness, the number of putative triggers that have been reported in the literature, some immediate and others long-term and additive, is huge.

- Discharge from prisons hospitals and care
- Leaving asylum support accommodation
- Patterns of addiction
- Failed asylum seekers/visa overstayers
- Offending
- Unemployment or redundancy
- Experience of street begging
- Poor acquisition of qualifications
- Consequence of debt
- Thrown out by parents families and relatives
- Family and relationship breakdown
- The ending of a rental tenancy or eviction
- Leaving local authority care
- Consequence of migration
- Long-term partner died and family fragmentation
- Home repossessed
- Living in poor quality, unsafe accommodation
- Leaving the Armed Forces
- Experience of the care system
- Involvement in sex work
- Mental health problems
- Experience of domestic violence or sexual abuse
- Difficulties during childhood (in families and at school)

People experience these triggers and life events in an infinite number of ways. Some manage to avoid being pushed off course by their own financial and other resources, by qualities of self-reliance and resilience, by the strength of their friendships, and by the absence of other underlying problems such as poor mental health or addiction to drugs or alcohol which may compound their exposure to the risk of homelessness.

The JSNA Process

A key issue with the preparation of JSNAs is that there is likely to be substantially less evidence on the nexus of factors that lead to a person being homeless or becoming a sex worker, for example, than on what happens to them once they have achieved that state. The act of becoming homeless or entering sex work triggers data collection in routine datasets as the individual can now be categorised by bureaucratic or administrative processes. Efficacy

of capture is likely to be an important consideration in these needs assessments (especially when a single category or subset of categories - such as an ethnic identifier - has the potential to capture vulnerability globally). If the majority of members of a group are regarded as vulnerable, then it would clearly be efficient to use the 'group-based' approach. Those who are on a trajectory to becoming homeless or at risk of working on the streets but, through personal circumstances, manage to avoid that outcome – the 'almost homeless' or 'sex worker avoiders' remain largely invisible in these data collection processes as they do not attain category status. Yet it is clear that some who experience vulnerability cycle in and out of these states at various times, as is evident from the data available on rough sleeping: over half of London's rough sleepers were sleeping rough for the first time while a quarter to a third had been sleeping rough for two consecutive years; however, an eighth were 'returners' who had slept rough in London in the past but not in the immediately preceding year[4]. Moreover, a much higher proportion of the stock of rough sleepers (including 'returners') had a history of some of these markers such as prison and the care system than first time rough sleepers.

Turning to the triggers themselves, while there are some existing measures already collected that identify known risk factors (e.g. people leaving prison, overcrowding, and people leaving care), some are not routinely collected in any datasets and for others measurement issues have not been fully addressed. When information on some of these triggers is collected, the datasets may encompass a selection but will exclude others and some potentially useful candidates may exclude the outcome of interest (in this example, homelessness and sex work). A triggers approach, however, may have some utility in identifying a broad spectrum of vulnerability (all those groups on the Health Inclusion Board's 'long list') and several studies based on the ONS Longitudinal Study are exemplars. When the focus is on a small subset of vulnerable populations and the experience of 'groupness' or group identity is strongly implicated in a person's vulnerability (as it is in the experience of asylum seekers and Gypsies/Irish Travellers), the trade-off between the different approaches favours the group-based. Moreover, a group-based approach may help catalyse participatory decision-making in the JSNA process allowing the vulnerable groups to be co-producers of knowledge, information, and services.

The pros and cons of identifying these vulnerable groups via the two approaches may be summarised as follows:

> *(1) A triggers or risk factor approach.* This would focus on risk factors or triggers and those factors that might protect a person (their resilience, friendship networks, etc.), and would require a 'pathways approach' or 'sequence analysis'. The difficulty with this approach is that, as has been noted, there is no necessary or sufficient set of factors that push people into any one of these vulnerable groups: usually it is a unique combination of 'triggers' and the absence/presence of 'protective factors'. While some covariates occur with greater frequency than others, none are 'necessary' or

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[4] http://www.natcen.ac.uk/study/profiling-london's-rough-sleepers/our-findings;
http://www.broadwaylondon.org/CHAIN/CHAINResearch/ProfilingLondonsRoughSleepers2009/main_content/ProfilingLondonsRoughSleepersFullReport.pdf

'sufficient' preconditions. Moreover, the JSNA process is concerned with health inclusion/health inequalities at local authority level, a relatively low-level spatial scale. Some of the numbers in the vulnerable groups may be small at local authority level, for example, many local authorities have less than 10 rough sleepers at any one time. While research elucidating pathways is needed as general context for these JSNAs and is key to the health inclusion strategy, particularly that focusing on prevention, the likelihood of data being available at the local authority level on the pathways for those who become vulnerable is negligible. Thus, collecting data anew through qualitative research studies would be needed.

(2) *A group-based approach*. Public health analysis has traditionally used groups or categories in studies of health inclusion and inequalities. Nearly all routine data collection that informs population health is based on categorisation, age, gender, and ethnicity being the most frequent variables. In the context of vulnerability, however, the use of categories or groups to define vulnerability tells us little about how the person entered or reached that state and, indeed, the role played by agency in some cases. Given that the JSNA process does substantially rely on the analysis of existing data, it tends to make greatest use of data that has been collected and reported. However, there are arguments based on validity that can be made that initiating a research process to collect data anew through qualitative research methods is also needed. While most local authorities are able to draw upon some routine data for all four groups, relatively few JSNAs at present engage in primary research for this purpose.

(2.1) Defining the 4 groups (vulnerable migrants, sex workers, Gypsies and Travellers, and homeless people) as 'vulnerable'.

Nearly all categories and groups used in public health are not homogeneous but conceal heterogeneity. Clearly, this may be a drawback if such systematic within-group heterogeneity correlates with different health outcomes. People living rough on the streets have very different health experiences to those living in local authority temporary accommodation as a 'priority' group. Similarly, the experience of Gypsies / Travellers in bricks and mortar housing may be different from those living, for example, in caravans on unauthorised encampments. An argument for a group approach is strengthened if nearly all people in the group experience vulnerability, that is, if the category or group has both high sensitivity and high specificity in capturing a vulnerable population. For example, the Gypsy/Traveller group as a whole may be legitimately regarded as vulnerable given the stark evidence on health status, the low levels of secondary school enrolments and of educational attainment, high levels of entitlement to free school meals (indicative of financial deprivation), and poor contact with health services. Indeed, Ofsted specifically highlights Gypsy, Roma, and Traveller pupils as a 'vulnerable group' in the revised Ofsted framework.

Similarly, *all* refused asylum seekers could be regarded as vulnerable, given the high prevalence of depression in the group, the frequency with which they are found in local authority destitution audits, and their lack of eligibility for many categories of NHS treatment.

For other groups where the spectrum of vulnerability is large, this approach may be satisfactory from the viewpoint of *sensitivity*, that is, in capturing those who are the most vulnerable, for example, use of a 'homeless' category or group will capture those who are rough sleepers and those in the hostel system. However, it will have poor *specificity*, that is, it will also capture many who are less vulnerable, such as those who are living in local authority housing as a 'priority' group or in unsatisfactory/overcrowded accommodation (but who may still be at risk of homelessness and in unsettled/temporary accommodation which can damage health and wellbeing).

(2.2) ***Defining a spectrum of vulnerability within the 4 groups:*** Where vulnerability is not specific to the group as a whole or is characterised by a wide range across the group, an approach may be needed that endeavours to identify predominantly vulnerable subgroup(s) encompassed by the category or group. Given that JSNAs are undertaken at the local authority level, this seems to be the optimal approach from the viewpoint of operationalizing 'vulnerability' at this spatial scale. Moreover, this approach draws on the way in which vulnerability has been addressed by the Inclusion Health Board with respect to some of the prioritised groups. For example, in defining the vulnerable homeless, the Department of Health's Office of the Chief Analyst includes rough sleepers and those in the hostel system or other forms of short-term/insecure accommodation but excludes those living in temporary local authority accommodation under homelessness legislation and people living in overcrowded or unsuitable accommodation. It should be feasible to operationalize this approach at local authority level using existing data collections and therefore provide a *modus operandi* for undertaking JSNAs.

3. IDENTIFYING A SPECTRUM OF VULNERABILITY IN THE SPECIFIED GROUPS

The approach adopted focuses interest on vulnerable population subgroups in the populations of the four groups. In the case of all four groups there is a spectrum of vulnerability. In the homeless group, for example, those rehoused under statutory homelessness legislation may not be regarded as vulnerable by agencies concerned with health inclusion and those experiencing such homelessness may not see themselves as vulnerable. However, those living rough on the streets would unequivocally be regarded as vulnerable by government and, given the magnitude of the burden of co-existing mental health problems, drug and alcohol addiction, and premature death, most of the rough sleeping population would no doubt identify themselves as vulnerable. The following section attempts to define what this spectrum of vulnerability is, should those commissioning services wish (at least initially) to prioritise services for particular segments of the population who are the most vulnerable.

Vulnerable migrants

There are many different kinds of migrants: refugees, asylum seekers and those refused asylum, EU and other overseas migrant workers, family reunion migrants, international students, trafficked persons, and undocumented migrants There is likely to be a wide spectrum of vulnerability amongst these migrants, for example, many long-settled migrants, new migrants who have come to Britain as highly skilled or skilled workers with a job offer (tier 1 and 2 overseas workers), international students, and family reunion migrants may not be vulnerable (though a small number may become vulnerable). At a *subgroup* level, however, many asylum seekers (and especially failed asylum seekers), trafficked people, and otherwise undocumented migrants would be regarded by others and probably see themselves as vulnerable.

Groups with greater vulnerability may include:

- Asylum seekers suffering from anxiety, depression, and PTSD associated with their experiences in their countries of origin (where they may have been victims of imprisonment, violence, torture and rape) and difficult migration journeys. Such problems may continue to affect those granted refugee status. The evidence of late onset of PTSD in some samples of children and of delayed recovery (even after a dozen years) may have implications for commissioning services.

- Asylum seekers & other migrants with high rates of acute/chronic disease are a vulnerable group, e.g. migrants from sub-Saharan Africa with HIV / AIDS, who may present late for fear of the effect that disclosure would have on their asylum applications, and who consequently frequently have advanced disease at diagnosis.

- Failed asylum seekers - those who receive minimal section 4 support (accommodation and vouchers) and those who do not comply with the conditions for such support (and consequently have no recourse to public funds) - are well documented as a vulnerable group. They are frequently mentioned in the 'no recourse to public funds' population and enumerated in destitution audits. Some studies report that up to half in this population are suffering from depression. Moreover, given that a proportion of all failed asylum seekers choose to remain in the country, the cumulative total is now large, with estimates of 510,000 across the UK (70% or 360,000 in London) at the end of 2007. This group have only limited entitlements to health care.

- Unaccompanied asylum-seeking children and young separated asylum seekers/refugees are vulnerable by virtue of their age (some are under 16, though most are older) and the fact that the majority have no parent or guardian in the country. Those who are refused asylum frequently have poor access to public funds and resources and adverse experiences if they are detained.

- Undocumented migrants (mainly people who have entered the country illegally & not via the asylum seeking or visa processes) are largely invisible in official records and have few if any entitlements to services including healthcare. Some work in low paid and/or irregular occupations with minimal regard for health, sanitation, and safety under the authority of gang masters.

- Migrants who have been trafficked are vulnerable and their circumstances may be exacerbated if they are criminalised or sent to immigration detention centres. Some of these migrants may have been sexually/physically abused and forced into the sex industry.

- Rough sleeping A10 (Eastern, Central, and Southern European) migrants[5] are found in significant numbers amongst the rough sleeping population of London and other cities, their position being compounded by weak welfare protection (minimal recourse to public funds). Some may be seasonal migrants homeless during the winter season. Alcohol support needs are particularly high in this group (e.g. over 70% of Polish first rough sleepers). They also tend to eschew short-term accommodation (in contrast to the wider rough sleeping population who access short-term accommodation at some point).

- Some new migrants who have not yet undergone health assessments, GP registration, or engaged with healthcare providers, may be vulnerable. For example, this group may include some Slovak Roma who have been arriving in Britain since Slovak Republic accession in 2004 and have been described as 'one of the most deprived of

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[5] The 2004 A-8 accession states: Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia, plus the 2007 accession states, Bulgaria and Romania.

EU residents': they are marginalised and subjects of recognised health inequalities in their country of origin[6]. As they are not subject to any formal assessment processes (in contrast with asylum seekers), they frequently experience little new immigrant health screening on arriving in a particular local authority.

Gypsies and Travellers

The Gypsy and Traveller community is a population that could reasonably be argued is vulnerable at a *group* level, for example, its health status is much worse than that of the general population and even socio-economically matched comparators and levels of educational attainment, school exclusions, absences from school, and eligibility for free school meals clearly place the group as an outlier. Moreover, the group probably has the most severe and consistent experiences of racism of any group[7]. The Inclusion Health Board has suggested a focus on Gypsies / Irish Travellers with the worst health outcomes.

- One of the main determinants of vulnerability and poor health outcomes relates to Gypsy/Travellers' housing situation. Studies have shown that Gypsy/Travellers on unauthorised sites (accounting for around 20% of caravans), including roadside and transit sites, have poorer outcomes arising from poorer access to amenities (like showers and toilets), poorer access to and continuity in their care[8], and in their children's attendance at school, and less protection against eviction. Travellers on unauthorised sites may be more exposed to hostility, hate crimes, and racism, all these factors exacerbating inequalities and limiting life chances. Forced evictions may significantly affect the health and well-being of individuals and families. The Equality & Human Rights Commission argues that site occupancy is a key source of vulnerability for Gypsy/Travellers, focusing specifically on shortage of caravan sites, poor site development and maintenance, and failure to follow-up Gypsie/Travellers after eviction (linking these concerns with the right to a home under article 8).

- Financial deprivation in the Gypsy and Traveller community may contribute to vulnerability. The annual school census shows a strong link between underachievement and material deprivation, which may be associated with low levels of parental literacy and (amongst recent Roma migrants) poor understanding of English. 43.2% of all pupils registered as Roma, Gypsy, or Traveller are currently eligible for free school meals; this figure rises to 45.3% in secondary schools and 57.5% in Special schools. Some studies suggest that less than one in ten

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[6] G Gill. The health needs of the Slovak Roma community in Sheffield. *Community Practitioner* 2009; 82(3):34-7.

[7] For example, nearly half (48%) of the sample in the 2006 Scottish Social Attitudes Survey thought a Gypsy/Traveller would be unsuitable in a role as a primary school teacher (similar proportions thought this of a person who experiences depression or someone aged 70 or over). Just 15% thought a Muslim would be unsuitable and 5% in the case of Black/Asian persons.

[8] One study found that 95% of travellers on authorised sites in 5 London boroughs were registered with a GP but only 56% on unauthorised sites (Hyman M. *Sites for Travellers – a study of 5 London boroughs*. London: London Race and Housing Research Unit, 1989).

Gypsies/Travellers of working age are in employment. While there have hitherto been no statistics that record employment and unemployment levels, this has been remedied by the 2011 Census, which revealed that only 51% of those who were economically active were employed, compared to 75% for the total of England and Wales[9]. Gypsies / Irish Travellers have now been included in the Labour Force Survey and Integrated Household Survey) and claims for out-of-work benefits in the Gypsy / Irish Traveller population. Moreover, the Department for Work & Pensions had made a commitment to include Gypsies / Travellers as a monitoring category in its IT, processing and management information systems with the introduction of Universal Credit in 2013.

- The health experiences of some Gypsy and Traveller groups are so much worse than their counterparts that (following the Inclusion Health Board's intent to focus on the worst outcomes) they should be designated as particularly vulnerable. *Male Irish travellers* in Ireland have a *suicide rate* 6.6 times higher than the general population; *Gypsy Travellers* in the Thames Valley have a 100-fold excess risk of measles arising from *low immunisation*. The report of the Confidential Enquiry into Maternal Deaths in the UK, 1997-99, found that Travellers have 'possibly the highest *maternal death rate* among all ethnic groups'. These population health findings based on robust data are stark and require urgent public health focus, including targeted suicide prevention services, a robust system of reporting of infectious diseases in the Gypsy/Traveller population and of levels of immunisation (both currently absent), and a robust system for monitoring maternal mortality (also absent).

Homeless people

'Homelessness' is poorly defined. It may comprise the rough sleeping population, single homeless people living in hostels, shelters and temporary supported accommodation, statutory homelessness, that is, those who have a duty owed to them under the homelessness legislation, and hidden homelessness (concealed, sharing & overcrowded households). Many within the priority groups that encompass the statutory homeless may be regarded as less vulnerable, for example, as much local authority temporary housing for priority groups (such as families with children) is now frequently long-term. While long-term living in unsettled accommodation is still a marker of vulnerability, the situation of such groups contrasts with rough sleepers and those in similar insecure settings.

Homelessness, from a health inclusion perspective, includes the following, sometimes overlapping, groups: people sleeping rough, people sleeping in a hostel, and people in insecure or short-term accommodation, such as in a squat or on a friend's floor, who cycle into rough sleeping and the hostel system, and people living in temporary accommodation provided by local authorities under homeless legislation (which may include families with children) and those living in overcrowded or unsuitable accommodation. A March 2010

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[9] ONS. *What does the 2011 Census tell us about the characteristics of Gypsy or Irish Travellers in England and Wales.* London: ONS, 2014 (21 January). http://www.ons.gov.uk/ons/dcp171776_349352.pdf

report by the Department of Health's Chief Analyst reviewed the health needs of the first 3 groups and concluded: 'It is generally agreed that these people are vulnerable, have particularly high health needs and are hard to reach through mainstream services' [10]. The differences in legislative status between different subsets of homeless people have made it difficult to measure vulnerability and compare health needs across all the subsets of homelessness.

The following subgroups may be defined as having higher vulnerability amongst the homeless population:

- People living/sleeping in the least secure setting - <u>living rough on the streets</u> - are one of the most vulnerable of homeless groups (numbering around 1800 nationally on any one night)[11], known to be at risk of violence, severe illness, & premature death. Amongst first time ('flow') rough sleepers in London, those with support needs over the 7 years 2001/2 through 2007/8, ranged from 39.4-46.7% for alcohol, 28.9-46.6% for drugs, 31.1-42.8% for mental health, and 32.8-44.1% for physical health[12]. The proportions have declined over the 7 years (reaching their lowest level in 2007/8) for all groups except alcohol, where they have increased over the 7 years, levelling out somewhat since 2004/5. The proportions are higher amongst the 'stock' and 'returner' groups: for example over half in the 'returners' group had drug and alcohol support needs. Around 86-89% of first time rough sleepers are male with a median age of 39 years, following a decline in young rough sleepers, and around 37% are now from minority ethnic groups. Significant but declining proportions have had an institutional history of prison or care (factors affecting resilience to prevent or leave homelessness), but over half had an experience of prison in the 'returners' group.

- Single homeless people, including <u>those in insecure accommodation such as those living in first stage, short-term hostels (direct access and emergency/night shelters), squats, or sleeping on friends' floors</u>, and those who have a history of rough sleeping (but excluding those in local authority 'priority' accommodation). This group along with rough sleepers are often defined as the 'no fixed abode' population and data from specialist practices indicates that they also have significant support needs with respect to alcohol, drugs, and mental health. They frequently also experience spells of rough sleeping.

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[10]

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114369.pdf

[11] The autumn 2012 total of rough sleeping counts and estimates in England was 2,309; London had the highest number of rough sleepers with 557, almost a quarter of the national figure. The latest report based on the CHAIN database showed that a total of 5,678 rough sleepers were contacted by outreach workers or building based teams in London during 2011-12. See: Communities and Local Government. *Rough Sleeping Statistics England – Autumn 2012. Experimental Statistics*. London: CLG, 2013 (February).

[12]

http://www.broadwaylondon.org/CHAIN/CHAINResearch/ProfilingLondonsRoughSleepers2009/main_content/ProfilingLondonsRoughSleepersFullReport.pdf

- People who <u>belong to more than one vulnerable or client group that includes homelessness</u>, e.g., people with co-existing poor mental health and drug and alcohol problems (dual diagnosis), people who have recently experienced family fragmentation, refused/destitute asylum seekers, sex workers, etc. Homeless people may be vulnerable by virtue of the cumulative nature of their disadvantage and lack of recourse to remedies. Among first-time rough sleepers in London in 2007, around a fifth had a mental health problem combined with a drug or alcohol support need.

- <u>Homeless people with dependent children</u> may fall into the vulnerable category (though many are in temporary Local Authority accommodation and are not vulnerable).

- <u>Migrant rough sleepers</u> may be a particularly vulnerable subgroup. They are disproportionately present in the rough sleeper population (notably, migrants from the EU Accession States): over half of London's rough sleepers are non-UK nationals (52%) & 28% are from East European countries. Those that are unable to find work or do not have recourse to public funds may be at risk, including persons granted leave to remain but who have to leave asylum-supported accommodation, failed asylum seekers who choose to stay in the country, and illegal entrants. This group may also include some new refugees: The Home Office Survey of New Refugees found that a small proportion (4%) of refugees in every sweep of the Survey of New Refugees lived on the street at some point between the baseline and 21 month follow-up (probably an underestimate as participation required a fixed address)[13].

- <u>Homeless young people</u>, especially 16 and 17 year olds and care leavers, may be vulnerable. While they are less represented in the rough sleeping population, they are still a significant part of the homeless population. Recent research[14] suggests that the number of young people who are homeless is growing with welfare changes set to increase this further.

Sex workers

'Sex workers' is a term that covers a wide range of individuals at risk[15]. There are 'street sex workers' selling their services on the street and 'off street' sex workers who may be working in a range of venues (saunas, brothels, massage parlours, their own homes). Male sex workers may offer their services in a range of venues, including public toilets. There is some evidence that under-18 sex workers are more likely to be working in off-street settings.

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[13] Cebulla A, Daniel M, Zurawan A. *Spotlight on refugee integration: findings from the Survey of New Refugees in the United Kingdom. Research Report 37*. London: Home Office, 2010 (July).

[14] See: Homeless Link. *Young and Homeless 2012*. London: Homeless Link, 2012 (December). Accessed at: http://homeless.org.uk/sites/default/files/Young%20and%20homeless%20report%202012.pdf

[15] The recommended public health language is 'sex worker' rather than 'prostitute' (although the latter continues to be used by the Home Office. See: http://www.phl.nhs.uk/docs/version_2_0_files/PHL_Version_2_0_alpha.pdf

There are particular groups of people who are at risk of becoming involved in sex work. Women are at higher risk than men. Some young people are particularly at risk, including those not in education, children who go missing from home, young people in care (looked after)[16] or leaving care, young people with parents involved in the sex industry, children living alone, and children living in a red light area. Of women who currently work in the sex industry, 33% were in care as a child, 25-45% were sexually abused as children, and 85% were physically abused as children. One study found that 78% of sex workers who were also problematic drug users had been in care[17].The Croydon Eclipse, based at Barnardos, is a multi agency project which works with young runaways and children at risk of sexual exploitation: during 2009, the team supported 39 individuals of whom 41% were looked after children[18].

Problem drug users are also at particular risk. Over the last two decades problematic drug misuse has become increasingly implicated in sex work, particularly that which is street-based. An estimated 98% of street-based sex workers are problem drug users, using heroin and crack and sometimes injecting. Many sex workers entered the business of sex working to fund an existing drug habit, whether that was their own decision or at the behest of drug-dealing pimps (it is claimed that around a fifth of female sex workers enter the business via pimps). Some sex workers may have started their habit having entered sex work, being surrounded by a drug-using social network. Nottingham's 2009 JSNA indicates that less than half of problematic drug users are in treatment, with men poorly represented.

Women experiencing domestic violence and/or rape may also be a vulnerable group. There is much debate about the association between sex working and experience of domestic violence. National data indicate that around 25% of sex working women experience domestic violence compared with around 10% of the general population. While the risk is increased, domestic violence is not necessarily a consequence of sex work. The Nottingham JSNA estimated that 50% of its street sex workers had experienced rape.

Other vulnerable groups may be street workers who are homeless. The Nottingham JSNA (2009) estimated that 90% of its street sex workers were homeless.

Women, young people, and children trafficked from abroad are at greater risk of becoming sex workers. Some may have been brought from abroad for the purpose of working in the sex industry, while others may be forced into it having arrived in this country. This sector is one of the most hidden and its members tend to be highly mobile.

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[16] Matthews, P (2000) A Review and a Way Forward: A report on the sexual exploitation of boys and young men. Barkingside, Essex: Barnardos; Palmer, T (2001) *No Son of Mine! Children abused through prostitution.* Barkingside, Essex: Barnardos

[17] Cusick, L and others (2004) *Vulnerability and involvement in drug use and sex work.* Home Office findings, (2007)

[18] Croydon Eclipse: *Invest to save evaluation: summary* (October 2009)

Workers in lap dancing clubs are also considered to be an at risk group for entering the sex industry as such clubs are known to be a gateway to sex working.

Although the evidence base is poor, that presented above enables some subgroups of vulnerable sex workers to be identified:

- National-level research has indicated that the sexual health needs of <u>street sex workers</u> tend to be more acute than those operating from private flats, street workers frequently having substance addictions (studies indicate that in excess of 85% reporting using heroin and 87% crack cocaine) and very chaotic lifestyles. They are the group with least stability, highest needs, and poorest health. While using some health services more heavily than the general population (GP, A & E, STI clinic, and inpatient and outpatient clinics), street sex workers, however, are less likely to have taken up routine screening, health checks, and vaccinations.

- <u>Children and young people, including care leavers</u>, who have been forced into sex work and are being sexually exploited may be particularly vulnerable.

- There is some evidence that <u>migrant and undocumented sex workers</u> may be off-street and may engage in more risky practices.

- People who have been <u>trafficked into the country for the purposes of sex work</u> and are being held captive by those exploiting and controlling them are particularly vulnerable.

4. HEALTH INCLUSION ISSUES

This section of the report will attempt to identify the main health inclusion issues. All four groups face discrimination and two (Gypsies and Travellers and vulnerable migrants) racialization and racism. All the groups suffer the double disadvantage of experiencing inequality in the context of the wider population (greater social exclusion, poorer health outcomes, and inequalities in the determinants of health) and difficulty in accessing health services in general and especially primary care.

It will attempt to address access to and use of health and social care services and will seek to identify where the main burdens of morbidity and mortality are located. Knowing these, it will be possible to prioritise issues regarding inclusion and gaps in data collection and monitoring.

However, definitional problems in all these populations have imposed limitations on the evidence base.

Vulnerable Migrants

The available literature focuses primarily of asylum seekers and refugees.

Use of services: Difficulties in accessing GP services and an increased reliance on A & E services, though 98% of refugees in the Survey of Refugees Living in London were registered with a GP & 88% chose GP as the most preferred service for treatment of illness; uncertainty and lack of clarity among service providers about asylum seekers' eligibility for secondary healthcare services; and low uptake of preventative healthcare measures (breast and cervical screening) have all been reported. Provision of mental health services for the survivors of torture and organised violence are widely regarded as patchy and inadequate. The Survey of Refugees Living in London found that of those who had experienced mental or emotional health problems, 40% reported that they had not received treatment[19].

General health: The Survey of New Refugees in the UK reported that refugees had poorer health than the general population in England and Scotland, those described as being in good health being more likely to be employed than other refugees. Poor health was also associated with slow improvement in English language skills over time. According to the Survey of Refugees Living in London, refugees were more likely to say that their health is poor (12% compared with 5% in the general London population).

Mental health: Mental health problems include post-traumatic stress disorder (PTSD), anxiety, depression and phobias, with rates up to 5 times higher than in the general population. A study of 800 Kosovan Albanian refugees settled in the UK yielded estimates of a PTSD diagnosis in just under a half and a major depressive disorder in around a fifth

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[19] Ipsos MORI. *A survey of refugees living in London. Report for the Greater London Authority*. London: Ipsos MORI, 2010 (September).

(Turner *et al.*, 2003). Research by Silvone *et al.* (2000) on destitute asylum seekers in SE England found that more than half were receiving medication for depression. Children, victims of torture, women, and LGBT asylum seekers may be particularly affected.

Antenatal care and maternal morbidity: There is evidence of late booking, poor antenatal care and poor pregnancy outcomes. A Confidential Enquiry into Maternal Death & Child Health (2004) found Black African women, especially including asylum seekers and newly arrived refugees, had a mortality rate seven times higher than white women.

Communicable diseases: A wide range of communicable diseases has been reported among asylum seekers and there are anxieties about low rates of vaccination among children and adults and the spread of multi-resistant TB. In a sample of 397 newly arrived asylum seekers in Sunderland and North Tyneside (Blackwell *et al.*, 2003), around only 16% of the sample or fewer had been vaccinated for measles, mumps, or rubella. Those vaccinated for TB were below that required to provide adequate population immunity.

HIV/AIDS: Migrants from sub-Saharan Africa are at increased risk of HIV/AIDS though no data has been found of prevalence of HIV/AIDS in asylum-seekers and refugees from this region. Several studies report that the policy of dispersal of asylum seekers has impacted adversely on those with HIV/AIDS.

Thus, with respect to data capture, sources that record use of services (primary and secondary care), mental health (especially PTSD & depression), communicable diseases (including HIV/AIDS), antenatal care, and birth outcomes are likely to be particularly important for the vulnerable asylum seeker/refugee population.

Gypsies and Travellers

Use of services: GP registration rates are low, often related to lack of proof of identity and of a permanent address, poor literacy / poor use of English (for Slovak & other migrants), & anticipation of discrimination from GP practices. A review of studies undertaken in 2005 found GP registration rates varying from 50-91%[20]. Parry *et al.* found that Gypsy Travellers were much less likely than their comparators to be registered with a GP (16% vs 1% not registered). Gypsies and Travellers were also less likely to visit the practice nurse, a counsellor, chiropodist, dentist, optician or alternative medical workers, or to contact NHS Direct or visit walk-in centres than their counterparts[21]. Given the problems accessing GP services, there is some evidence (including in this study) of significantly higher rates of use of A & E services.

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[20] Aspinall PJ. *A Review of the Literature on the Health Beliefs, Health Status, & Use of services in the Gypsy Traveller Population & of Appropriate Health Care Interventions.* Cardiff: Welsh Assembly Government, 2005.
[21] van Cleemput P, Thomas K, Parry G, Peters J, Moore J and Cooper C. *The Health Status of Gypsies and Travellers in England.* Sheffield: University of Sheffield, 2004 (October).

Generic health status: Gypsies and Travellers have poorer general health and higher rates of limiting long-term illness, after controlling for socioeconomic status, higher rates of cough or bronchitis, and higher rates of chest pain and asthma. Several studies have reported large gaps in life expectancy (men and women losing an average of at least 10 and 12 years, respectively), although life expectancy can be variable. Health expectancy deteriorates rapidly after age 50.

Mental health: Gypsies and Travellers are nearly three times more likely to be anxious than average and just over twice as likely to be depressed. The All-Ireland Traveller Health Study (funded by the Department of Health and Children & published in 2010) found that the male suicide rate was 6.6 times the rate in the general population[22]. The female rate was 4.9 times higher but not statistically significant. Another study found that suicide rates amongst Irish male Travellers were 3 times higher than in the general population[23]. No UK data has been identified: A UK wide study commissioned by EHRC recommended: '….that urgent research is undertaken into the prevalence of suicide and self-harm amongst Gypsy, Traveller…communities in Britain'[24].

Poor birth outcomes and maternal health: There is an excess prevalence of miscarriages (29% vs. 16% in a matched comparison group), stillbirths, neonatal deaths, and infant mortality in Gypsy and Traveller communities. The infant mortality rate in the All Ireland Traveller Health Study was 3.6 times higher in the Irish Traveller population than in the general population. Higher rates of maternal death during pregnancy and shortly after childbirth have been found in the traditional Travelling community than in the general population by some of the earlier reports of the Confidential Enquiry into Maternal Deaths[25].

Diabetes: A higher prevalence of diabetes has been reported in the Gypsy / Irish Traveller population. Type 2 diabetes was 3 times higher in a sample of Slovak Gypsies compared with a comparison group of non-Gypsies. Doctor diagnosed diabetes was twice as high in the Irish Traveller population than in the general population in the All Ireland Traveller Health Study. Parry *et al* (2004) also found more cases than in their comparators.

Low child immunisation rates and commensurate elevated rates of measles, whooping cough, and other infections: A number of studies have reported low immunisation rates for Gypsy & Traveller children[26] and an excess burden of measles infection[27]. In 2006 and again in 2010 there were a number of outbreaks (clusters) of measles within Gypsy & Traveller communities across the UK. The Director of Immunisation has noted: 'It is difficult to

[22] http://pavee.ie/ourgeels/

[23] Walker MR. *Suicide amongst the Irish Traveller Community 2000-2006*. Wicklow, Ireland: Wicklow County Council.

[24] Cemlyn S, Greenfields M, Burnett S, Matthews Z, & Whitwell C. *Inequalities Experienced by Gypsy and Traveller Communities. A Review. Research Report 12*. Manchester: Equality and Human Rights Commission, 2009 (Winter).

[25] Ibid, pp. 20-21.

[26] Feder GS, Vaclavik T, Streetly A. Traveller Gypsy and childhood immunization: a study in east London. *Br J Gen Pract* 1993; 43: 281-4; HPA. Laboratory confirmed cases of measles, mumps and rubella, England and Wales, October to December 2006. Immunisation. Health Protection Report 2007; 1(12).

[27] Muscat M. Who gets measles in Europe. *Infect Dis* 2011; 204: S353-65.

monitor uptake of the MMR vaccine within the Gypsy and Traveller community but it is our understanding that levels of immunisation are low'[28]. Large Gypsy & Traveller events during the summer may have exacerbated the outbreak. In 2012 there were several smaller outbreaks in the Traveller community and also some cases of pertussis (whooping cough). In a recent study of measles amongst Gypsies and Travellers in the Thames Valley, where Gypsy / Traveller ethnicity was specifically ascertained, 142 cases of laboratory confirmed measles were reported over 4 years (2006-9), with a median age of 6.5 years, 90 (63%) of which were Gypsies/Travellers: this represented an excess risk of more than 100-fold in these Gypsy/Traveller communities[29]. 55% of the Gypsy / Traveller cases were amongst children aged under 5. Of the 55 confirmed cases in the Gypsy/Traveller community eligible for vaccination, 27 (49%) had had one MMR vaccination.

Thus, with respect to data capture, sources that record <u>use of services (primary and secondary care)</u>, <u>birth outcomes</u>, <u>maternal morbidity and mortality</u>, <u>childhood immunisation rates</u>, and <u>mental health</u> are likely to be particularly important for the vulnerable Gypsy/Irish Traveller population.

Homeless people

Use of services: Single homeless people are five times more likely to use Accident & Emergency Services than the general public[30] and 3.2 times more likely to have hospital admissions (with three times the duration of stay). It has been estimated that homeless people consume around four times more acute hospital services and eight times the secondary care costs in the case of inpatient services than the general population[31]. Homeless people experience numerous barriers in accessing mainstream primary care, one 2002 study estimating that homeless people were forty times more likely not to be registered with a GP than the general population[32]. A more recent national audit of over 700 homeless people from across England found that, while 85% of clients had said that they were registered with a GP, the majority permanently, 15% remained unregistered and 9% indicated that they had been refused access to a GP or dentist[33]. Current provision of specialist primary care services is reported to be variable, around a third of PCTs not providing any specialist homeless services. The demand for such is clear from a specialist practice in Leicester which has 9000 consultations a year from 1000 patients with a 59% annual turnover. Permanent registration is more likely in areas with a large homeless population.

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[28] Department of Health. Director of Immunisation *Letter to Immunisation Co-ordinators & Local Directors of Public Health. Measles outbreaks in Gypsy & Traveller communities*. 22 July 2010.

[29] Maduma-Butsche A, McCarthy N. The burden and impact of measles among the Gypsy-Traveller communities, Thames Valley, 2006-9. *Journal of Public Health* 2012. Advanced Access, 24 July 2012.

[30] Healthcare for Single Homeless People. Office of the Chief Analyst, Department of Health, March 2010.

[31]

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114 369.pdf

[32] *Critical condition*. Crisis 2002.

[33] Homeless Link. *The Health and Wellbeing of People who are Homeless: Evidence from a National Audit*. London: Homeless Link, 2010. Accessed at:

http://homeless.org.uk/sites/default/files/Health%20Audit%20Findings_National%20evidence.pdf

Premature mortality: There is evidence that rough sleepers & those in hostels for the homeless have significantly higher levels of premature mortality, where deaths occur the average age at death being 40-44 years. At the Leicester specialist practice, the average age at death of 131 patients (out of a total of 4,407 seen over a decade) was 40.5 years. Alcohol was implicated in almost half the deaths and drug misuse in a quarter. Deliberate suicide was implicated in around 8% of cases (though with a decline over the decade). A further recent study using robust methodologies and data for England, 2001-09, reported that the average age of death of a homeless person is 47 and even lower at 43 for a homeless woman[34].

Mental illness: Poor mental health is frequently reported, including depression and other affective disorders, anxiety states, personality disorder, and schizophrenia. In London 39% of rough sleepers have mental health problems. Research by St Mungo's found that around half their residents had mental health problems[35]. It is estimated that up to 60% of people in the hostel population in England may suffer from personality disorder. In a study of consultations at a specialist homelessness practice over ten years, diagnoses of most mental illnesses have been fairly stable or slightly increased, comparing 2002/03 with 2008/09 (26-29.7% for depression, 9%-15.3% for anxiety, 5-7.7% for personality disorder, and schizophrenia 2.2-2.8%).

Drug/alcohol misuse & dependence: Early onset of drug misuse, severity of alcohol use, and drug/alcohol dependency are major problems. In London 52% of rough sleepers have alcohol support needs and 32% drug support needs. St Mungo's charity reported that 32% of their residents had an alcohol dependency problem and 63% had a drugs problem. In a study of consultations at a specialist homelessness practice over ten years, diagnoses of heroin dependence have fallen somewhat from 37 to 28% but alcohol dependence has increased from 20-29%: these findings are in line with national trends, confirming a shift from heroin to alcohol as the most prevalent drug of dependency amongst the homeless population (with clear implications for service planning and commissioning).

Physical illness: St Mungo's research found that 43% of their hostel residents had a physical illness, around a third of which were untreated. Respiratory problems (pneumonia, influenza, asthma, and tuberculosis, frequently latent), upper gastrointestinal disease, physical trauma (injury, foot trauma, and dental caries), blood-borne viruses, and skin problems (especially eczema) also occur more frequently than in the general population. Assault and fractures were reported in 17.5% and 28.6%, respectively, of consultations at a special practice for the homeless and many homeless have a lifetime experience of some form of trauma. Infestations (head lice, body lice, and scabies) are declining as a result of improved access to treatment.

Thus, with respect to data capture, sources that record <u>use of services (primary and secondary care)</u>, <u>mental health status and use of psychiatric services</u>, and <u>drug/alcohol misuse and use of related treatment services</u> are likely to be particularly important for the vulnerable homeless.

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[34] Crisis. *Homelessness: A silent killer. A research briefing on mortality amongst homeless people*. London: Crisis & Sheffield: The University of Sheffield, 2011 (December). Accessed at:
http://www.crisis.org.uk/data/files/publications/Homelessness%20-%20a%20silent%20killer.pdf
[35] St Mungo's. *Homelessness: It makes you sick*. September 2008.

Moreover, many homeless people have multiple health problems. The Office of the Chief Analyst has stated: 'Many homeless people demonstrate a tri-morbidity of physical illness, mental health problems, and substance misuse' Thus, sources that capture <u>dual or multiple diagnoses</u> or <u>sets of co-existing medical</u> <u>conditions</u> may be important.

Sex workers[36]

Limited access to services: The Department of Health's 2001 National Sexual Health Strategy identifies sex workers as a specific target group in need of sexual health information. It recommends that particular local strategies should be developed to meet their sexual health needs and that commissioners should have regard to developing accessible services: however, some evidence shows that male sex workers are detached from services geared to female sex workers. The Department of Health's 2010 Effective Sexual Health Promotion Toolkit for Primary Care Trusts includes advice on targeted work, including outreach services. The Home Office's 2006 National Prostitution Strategy also seeks to support those involved in sex work by promoting specialist services and focusing on prevention, harm reduction, and leaving sex work. Police authorities may also have a vulnerable person's unit that caters for sex workers. There may also be specialised children's services for safeguarding children from sexual exploitation.

Sexual health: Sex work carries a high risk of sexually transmitted infections (STIs) and blood-borne viruses (BBVs) for the sex worker (& also for the client), the risk of contracting such conditions increasing with the number of sexual partners a person has (in the case of sex workers, both paying clients and non-paying sexual partners). It has been estimated that 11% of male sex workers in London are HIV positive[37] (Croydon JSNA, 2010-11). Condom use in sex workers' private relationships is reported to be only 29%, though condom use in paid settings may be very much higher. 6% of female attendances at UK GUM clinics are sex workers.

Drug use: Over the last two decades drugs have become much more implicated in sex working. According to the government's Social Exclusion Task Force, 85% of street sex workers report using heroin and 87% using crack cocaine[38]. Other estimates for street sex work put the figure as high as 98% for problem users of class A drugs, mainly crack and heroin, some being injecting drug users. Amongst off street sex workers, problem drug use is less common[39] and tends to be speed or cannabis, with amphetamines amongst male sex

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[36] For a wider discussion of sex workers and social exclusion, see: Balfour R & Allen J. *A review of the literature on sex workers and social exclusion*. London: UCL Institute of Health Equity, 2013 (February).

[37] Legros F (2005) *A literature review of the sexual health needs of commercial sex workers and their clients* (PDF 86.4KB). Cambridge: DHIVERSE.

[38] HM Government. *Inclusion Health*: *Improving the way we meet the primary health care needs of the socially excluded.* London: Cabinet Office, March 2010.

[39] Cusick L. Female Prostitution in Glasgow: Drug Use and Occupational Sector. *Addiction Research* 1998; 6(2): 115-30; May T, Edmunds M, Hough M. *Street Business: The Links between Sex and Drug Markets. Crime*

workers. Of the total number of female sex workers case managed in Hackney over three and a half years, 50% were primary crack cocaine users and 26% primary heroin and crack cocaine users. Some sex workers may also be at risk of alcohol misuse. In Nottingham the JSNA (2009) estimated that women IDUs had nearly ten times higher risk of death and over 40% of women IDUs were infected with hepatitis C virus.

Mental health: Many sex workers have poor mental health, relating to a complex set of factors including their childhood, use of drugs, and social circumstances (including homelessness).

Domestic violence and sexual violence: Sex workers experience a high level of violence from partners, punters, and pimps. 75% of street sex workers have suffered physical violence; 70% of local sex workers reported having been raped or sexually abused. 54% of sexual assaults are perpetrated by a current or ex-partner. 40% have been threatened with a weapon. 13% have been abducted and held against their will. 25% of street prostitutes suffer domestic violence. Over a three year period, the Nottingham JSNA (2009) reported that 45 prostitutes had reported rape, likely to be a significant undercount. Sexual violence may be more salient when women have been trafficked into the country for the purposes of sex work.

Acute and chronic illness: Far higher levels of acute and chronic illness are reported amongst sex workers than the general population. A higher proportion of such illness remains untreated. Bristol's 2012 JSNA cites research in that city that showed that sex workers had poor nutrition and fluid intake and unsatisfactory sleeping patterns.

Antenatal/postnatal health: High levels of need have been reported due to high risk pregnancies and high postnatal baby morbidity and mortality. This is coupled with poor access to mainstream services and high levels of need for contraception and family planning services.

Thus, with respect to data capture, sources that record use of services (primary and secondary care), sexual health, drug misuse, mental health, and domestic/sexual violence are likely to be particularly important for the vulnerable sex worker population.

Detection and Prevention Series, Paper 118. London: Home Office, 1999; Sanders T. The Risks of Street Prostitution: Punters, Police and Protesters. *Urban Studies* 2004; 41: 1703-17.

5. USE OF ROUTINE AND OTHER DATA SOURCES FOR VULNERABLE MIGRANTS

5.1 Definitional issues and comprehensive denominator data

Disadvantaged and socially excluded migrants are a highly heterogeneous group with respect to migrants' experiences in their countries of origin and the migration process, their reasons for migration (including asylum-seeking), and their experiences in the country (either as temporary stayers during their time here as students, short-term workers, or as asylum applicants who are not successful, some of whom may remain, or as ordinary residents, including refugees). In the UK the term 'migrants' is frequently used to identify only recent arrivals[40], though many may have been in the country for decades. Thus attention has focused on flows of recent migrants, including asylum seekers/refugees, those coming via skilled worker programmes, and international students. There has been less focus on the wider population of generic migrants (those born outside the UK) that are identifiable through country of birth data who have been arriving in significant numbers in Britain since the early 1950s. There has also been little focus on the children of migrants, even though in some cases (such as the Irish) their health has been shown to be poorer than that of their parents.

2011 Census: The most comprehensive source on migrants (persons born outside the UK) is the England and Wales 2011 Census. This asked a question on country of birth: 'What is your country of birth' (with response options of: England, Wales, Scotland, Northern Ireland, Republic of Ireland and an 'Elsewhere' free text field to write in the name of the country). In addition, the 2011 Census for the first time provides information on how long the person has been in the country, the question asking: 'If you were not born in the UK, when did you most recently arrive to live here'. The respondent is prompted: 'do not count short visits away from the UK'. Space is provided to write in the month and year of arrival. The Census has also traditionally asked a question which enables recent migration to be captured (and this was included in the 2011 Census): The question asks: 'One year ago, what was your usual address? The response options include 'Outside the UK, write in country'. Finally (and new to the 2011 Census) there is a question: 'If you arrived on or after 27 March 2010, including the time you have already spent here, how long do you intend to stay in the UK?' (response options comprising: less than 6 months, 6 months or more but less than 12 months, & 12 months & more). Thus, data are now available for various levels of geography on:

- Persons who are migrants by country of birth
- How long these migrants have lived in the UK
- Persons who have migrated in the last year and their previous country of residence (staged migration can be identified by comparing country of residence with country of birth)

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[40] Jayaweera H. *Health and access to health care of migrants in the UK*. London: Race Equality Foundation, 2010.

- How long persons who have migrated in the last year intend to stay in the UK, providing some measure of short-term migration (that is, for a cohort who arrived on/after 27 March 2010 and are still resident in the country)

Many JSNA's will want data on migrant subgroups, including asylum seekers, refugees, skilled migrant workers, etc. The Census does not ask specific questions on these groups. Refugees, for example, are treated as part of the normally resident or general population. However, some measure of the heterogeneity in the migrant population will be available in the tabular data. For example, as tabulations of country of birth generally encompass a mix of individual countries and regions, this may provide a point of access to countries of origin that are likely to contain a significant proportion of asylum seekers/refugees, such as the Democratic Republic of the Congo, Afghanistan, Iran, Eritrea, Iraq, and Somalia. While sensitivity will be high, specificity may be poor for some groups such as those born in Somalia and Iraq. Census coding should permit the identification of international students. Further, country of birth data cross-tabulated by ethnic group, religion, national identity (new to the 2011 Census), and main language (also new to the 2011 Census) - available via standard outputs or commissioned tables - will provider finer granularity. The Census data can clearly differentiate recent arrivals from those long-settled, the former being more likely to be vulnerable though research findings indicate that in some groups health declines with length of time lived in the country and may even deteriorate in the second generation. However, with respect to the use of Census counts of migrants as denominators, there may be significant undercounts of some groups, such as failed asylum seekers who remain, other over-stayers, illegal/undocumented migrants, and trafficked persons. These are amongst the most vulnerable of migrant groups but remain largely hidden and impervious to endeavours at capture in administrative data.

However, one of the advantages of Census data is that there is a wealth of socio-economic data that will provide measures of vulnerability and disadvantage in the migrant population, including migrants who have poor general health, limiting long-term illness, those in shared houses and accommodation that is not self-contained, overcrowded housing, houses with poor amenities (lacking heating), those who cannot speak English, those with no qualifications, those who are unemployed, not working and long-term sick or disabled, or who have never worked. It will also be an important source of baseline data on the migrant population for JSNAs at the local authority or lower levels (Super Output Area tiers).

Several attempts have been made to infer or estimate the size of asylum-seeker and refugee populations from country of birth data in censuses and large scale surveys so methodologies are available. For example, Kausar and Drinkwater[41] differentiate four groups of migrants based on country origins: refugees and asylum seekers; mixed refugees and economic migrants; mainly economic migrants; and economic migrants.

Several other datasets provide comprehensive information on the migrant population.

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[41] Kausar R, Drinkwateer S. *A comparison of earnings and occupational attainment of refugees and asylum seekers and economic migrants in the UK. Discussion Papers in Economics DP 08/10.* Guildford: Department of Economics, University of Surrey, 2010.

Death registration data: The death registration process collects data on the country of birth of the person. This process also records cause of death. However, it may underestimate mortality in the migrant population as some migrants return to their countries of origin when in old age or poor health. Moreover, country of birth is a poor proxy for ethnicity. It excludes members of minority ethnic groups born in the UK and some countries of birth may conceal people who are White (whose presence in these country of birth data is explained by the country's colonial projects).

Birth registration data: Similarly, the birth registration process collects data on mother's country of birth but this will not identify minority ethnic mothers born in the UK. However, the data is comprehensive with respect to providing a count of children who are born to migrants once they become resident in the country.

NHS Central (GP) Register Flag 4. A flag 4 record is created when an individual registers with an NHS GP if the individual was born outside the UK (i.e. where the previous address is outside the UK) & enters England & Wales for the first time & registers with a GP. Clearly, this will not capture details of migrants who do not register with a GP and may therefore exclude some vulnerable migrants. Flag 4 data (migrant status) is based on the NHS Patient Register. Some triangulation of flag 4 data with other sources may throw light on aspects of health inclusion. For example, if Flag 4 GP registrations are much lower than NINO registrations, this may highlight an area where a low proportion of migrants are registering with a GP.

Sources that identify particular stocks and flows of migrants and migrant subgroups: There are in addition a range of sources that identify particular stocks and flows of migrants and migrant subgroups:

- *International Passenger Survey based ONS estimates of total international migration:* This source is problematic for local estimates. Though the main source of official information on people entering and leaving the UK, it is based on a sample of a very small proportion of all people entering or leaving the UK. The count is allocated to local authority areas on the basis of the LFS, thereby giving an estimate of Total International Migration (TIM) for each local authority area. The Office for National Statistics (ONS) has set up a task group to improve estimates.

- *National Insurance Number (NINO) Registrations*: These are allocated to non-UK nationals intending to work legally as employees or self-employed. Records show arrival date, registration date and country of origin, as well as postcode, which allows mapping to local authorities. This source will not record details of migrants who are not able to work such as asylum seekers, refused asylum seekers, and all non-working dependents. It does not capture people who move on after initially entering the UK.

- *Workers Registration Scheme (WRS):* Covers citizens of the A8 countries which became EU Member States in May 2004 (excluding Malta and Cyprus), who register to work as employees in the UK. Bulgaria and Romania have been added since their accession in 2007.

- *The UK Borders Agency (UKBA)* supply details of all dispersed asylum seekers to Primary Care Trusts, including name, nationality, gender, age and address. In previous years, there was no way of determining if individuals had travelled to the intended dispersal centre, but now the New Asylum Model involves initial processing at an induction centre in the dispersal area.

- *Electoral Registration data*: As a source of data on migrants, the drawback is under-registration. Name recognition software can be used to identify particular ethnic groups. This source scored the poorest amongst three others (local authority sources, ONS statistics, Workers Registration Scheme) in a study of the health needs of migrants in the South East Region[42].

- *The Higher Education Statistics Agency (HESA) records*: HESA maintains records on all students in the UK whose usual residence is outside of the UK. The data only relates to the institution of study, rather than area of residence.

- *Annual School Census*: This database is maintained by the Department for Children, Schools and Families and contains information on all state school pupils, including address, age, ethnicity, and first language. Details for local populations can be obtained from Local Education Authorities or commissioned from DCSF. Some local authorities use detailed ('extended') ethnicity codes which may provide indicative evidence on asylum seekers/refugees via specific countries of origin. However, in Scotland, the Annual School Census collects both 'refugee' and 'asylum seeker' status: data are published, tabulated by ethnic group[43]. This might be used to argue for the inclusion of these data items on the Annual School Censuses in England and Wales. While the Census in England does not collect information on refugees and asylum seekers, some education authorities in England do record this information at a local level. For example, the 2010 JSNA for Nottingham City reported that in May 2009 there were 319 asylum seeker children and 567 refugee children attending 87 of the Nottingham City primary and secondary schools. This authority also reported a known 146 asylum seeker children below school age & 58 above school age.

- *Unaccompanied asylum-seeking children:* The Home Office publishes statistics on unaccompanied asylum-seeking children. Between 2006 and 2009 these varied from 3,174 to 4,285 annually but fell to 1,717 in 2010. Most applicants are received in-country rather than at ports and most are male. Detailed information is also kept on unaccompanied minors or unaccompanied asylum-seeking children under 18 years of age by local authority social service departments as they are required to treat such children as 'Looked After Children' under Section 20 of the Children Act (1989). Data on such children supported in local authorities is collected by Children's Services and centrally reported.

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[42] http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1284475770868
[43] The 2011 Scotland School Census included 702 asylum seekers and 1,742 refugees (the main ethnic category being 'African'). Most were resident in Glasgow. See: www.scotland.gov.uk/Resource/0038/00388991.xls

5.2 Recording of vulnerable migrants (asylum seekers and refugees) in routine health and social care datasets[44]

5.2.1 General practice/primary care services

At general practice registration country of birth is recorded and occasionally refugee and asylum seeker status, though data is not available on the prevalence of recording of these items. As noted, the UK Border Agency (UKBA) now supply details of all dispersed asylum seekers to Primary Care Trusts, including name, nationality, gender, age and address. In Sheffield, for example, UK Border Agency Accommodation Providers provide the contact details of new asylum seeker arrivals direct to a PMS General Practice run by Sheffield PCT Provider Services. Similarly, in Dudley PCT, the main accommodation provider for asylum seekers supplies the PCT with details of the movement of asylum seekers[45]. It is not known whether this information is used as a basis to compile information on the number of asylum seekers in a PCT area or on their health. Record linkage is a further source of data on extent of registration, a recent study linking new entrants to the UK, documented by port health tuberculosis screening processes, with the Personal Demographic Services (PDS) Database[46].

5.2.2. Hospital services

There is currently no recording of asylum seeker, refugee, migrant/country of birth or migrant subgroups in the **HES Datasets** (HES Admitted Patient Dataset; HES Outpatient Dataset; A & E HES Dataset; PROMS Dataset; Adult Critical Care Dataset; and HES-ONS Linked Mortality Dataset).

5.2.3 Mental Health Services:

The _Mental Health Minimum Data Set_ (MHMDS) has not included data items on refugee/asylum seeker status nor on country of birth. However, with the closure of the Count-Me-In annual censuses, a 'Referral Route' code has been added to MHMDS standard codes. The 22 codes for this data item include 'Asylum Services'. This 'Referral Route' coding was used on the _2010 National Mental Health and Learning Disability Ethnicity Census_[47]. The Census did not collect data on country of birth.

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[44] An earlier review undertaken in 2006-7 identified the use of 'asylum seeker' and refugee codes on routine health and social care datasets. See: Aspinall PJ. The extent & collection of information on migrant & asylum seeker status in routine health and social care data sources in England. _International Journal of Migration, Health & Social Care_ 2007; 3(4): 3-13.

[45] West Midlands NHAIS Steering Group, Minutes of Meeting, 9th March 2011.

[46] Stagg HR, Jones J, Bickler G, et al. Poor uptake of primary healthcare registration among recent entrants to the UK: a retrospective cohort study. _BMJ Open_ 2012;2:e001453.doi:10.1136/bmjopen-2012-001453.

[47] https://www.countmeinonline.co.uk/docs/Protocol%20Document%202010.pdf

However, the *Child and Adolescent Mental Health Services (CAMHS) Dataset* has a 'Citizenship Status' field that includes codes for: Foreign National Visiting, Foreign National with Residency, Asylum Seeker, Refugee Status Granted, and Exceptional Leave to Remain. There is also a country of birth field.

5.2.4 Maternity care

In the *Maternity Services Secondary Uses Dataset* the mother's demographics include 'Refugee/Asylum status' (whether or not the mother is a refugee or seeking or given asylum during the pregnancy) and 'Country of birth (mother)'.There are also data items on 'country of origin' of mother and of father. It has not been possible to assess the utility of this coding in reported statistics from the dataset.

5.2.5 Child Health

The *Children's and Young People's Health Services (CYPHS) Data Set* (still in development) contains a data item on 'Refugee/Asylum Status' or 'Immigration Status' (whether or not a child/young person is seeking asylum or has been granted refuge). The stated purpose for inclusion is 'used to identify group associated with vulnerability or less likely to access services'. The values are: 'application for asylum applied for / refused / granted'; 'humanitarian protection'; 'temporary / discretionary / exceptional / indefinite leave to remain'. There are also data items on 'country of birth (refugee or asylum seeker)' and an 'Unaccompanied' identifier.

5.2.6 Asylum-seeking children in need and looked after:

The Department of Education's child level *Children in Need (CiN) Census* (referrals, assessments, and children who were the subject of a child protection plan) uses a flag to identify asylum seeking children and the date they ceased to be asylum seeking. The Department of Education's *Children looked after by local authorities in England* return includes information on the number of unaccompanied asylum-seeking children (UASC). There were, for example, 2,680 UASC who were looked after at 31 March 2011, a decrease of 22% from 2010. 75% are aged 16 years or over, 89% are male, and the majority are of 'Other Asian background' ethnicity (a shift from 2007 when most were 'Black African')[48].

5.2.7 Infectious / communicable diseases

Country of birth and other indicators of migrant status are much more likely to be recorded in infectious diseases databases as being a migrant is a risk factor for some of these diseases. The *Genitourinary Medicine Clinic Activity Dataset* contains a

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[48] http://media.education.gov.uk/assets/files/pdf/s/main%20text%20sfr212011.pdf

'Country of Birth' field. However, there is no coding for asylum seeker or refugee. The new *HARS Dataset* for (HIV/AIDS) (that replaces Survey of Prevalent HIV Infections Diagnosed [SOPHID] and surveillance of new diagnoses of HIV infections) contains a 'patient's country of birth' field. Related fields that may be of utility include: 'country of infection' (country where patient was likely to have been infected with HIV) and 'Year of UK arrival' (year patient arrived in the UK). The Enhanced Tuberculosis Surveillance (ETS) Dataset, which began on 1st January 1999 in England and Wales, contains a country of birth field.

5.2.8 *Health Surveys*

Some health surveys identify country of birth, for example, the *Health Survey for England* which, in the years 1999 & 2004, included an enhancement for minority ethnic groups. However, the NHS GP Patient Survey, conducted by Ipsos MORI and now in year 6, does not. There are also some Europe-wide health surveys that collect country of birth, such as the *European Health Interview Survey*. However, a 'variable search' on ESDS surveys and databases and text search of Survey Question Bank surveys revealed that there are scarcely any specialised surveys (with the notable exception of the Home Office Survey of New Refugees, 2005-09) or routine surveys that capture asylum seekers or refugees.

5.3 Major Gaps

Refugees: The exact number of refugees living in local authority areas and their health status is generally unknown. On being granted refugee status, leave to remain, humanitarian protection, or discretionary leave, individuals are free to migrate and move addresses. There are no administrative reasons for their status to be flagged in datasets as they are ordinarily resident in the country. Some attempts have been made to prepare synthetic estimates of such numbers[49]. The April 2010 JSNA for Nottingham City estimated that there were 7000 refugees in Nottingham, more than eight times the number of asylum seekers being supported by UKBA in that city.

Failed asylum seekers: No routine information is collected at local authority level on the number of failed asylum seekers who remain in the UK and of their health status. This group is likely to be amongst the most disadvantaged and vulnerable of migrant groups. Most estimates at local authority level are synthetic, based on national estimates (see 2010 JSNA for Nottingham City, which estimated 500 failed asylum seekers in that city). Some local authorities collect information on the *'No Recourse to Public Funds' (NRPF) population*, a category that generally includes failed asylum seekers. 'No recourse to public funds' is defined as 'a person subject to immigration control; has no entitlement to welfare benefits, public housing or Home Office asylum support; and does not have the right to work'. Such

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[49] Counting up: A study to estimate the existing and future numbers of refugees in the East Midlands, September 2006.

people may have entered the country illegally and are not known to the authorities; be visiting the country on a student or visitor visa or have overstayed a student, visitor or spousal visa; have been given limited leave to remain in the country on the condition that they cannot claim any public funds; be European Economic Area citizens; or a failed asylum seeker'[50]. Little evidence has been found of local authorities reporting numbers (caseloads) of 'no recourse to public funds' individuals or families, though this may be a source of data where more systematic collection could be encouraged, if not a dataset. In addition, 'destitution audits' undertaken in local authority areas by voluntary agencies frequently report failed asylum seekers amongst the destitute they enumerate[51].

Undocumented/illegal migrants: This group remain largely hidden and only become visible through UKBA efforts to identify those illegally working in the UK. It is unlikely that reliable estimates can be derived for local authority areas.

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[50] Lewisham Safeguarding Children Board. *Inter-agency Information. Guidance to No Recourse to Public Funds families.*

[51] For more on this source and a review of findings, see Aspinall PJ & Watters C. *Refugees and asylum seekers: a review from an equality and human rights perspective. Research report 52*. Manchester: Equality and Human Rights Commission, 2010 (esp. 'poverty, destitution and access to accommodation and financial support', pp. 57-75).

6. USE OF ROUTINE AND OTHER DATA SOURCES FOR GYPSIES AND

   TRAVELLERS

This section focuses on data sources that provide comprehensive and robust denominator data for the Gypsy and Traveller population and the capture of the Gypsy/ Traveller population in routine datasets.

6.1 Comprehensive denominator data: 2011 Census

The issue of the size of the Gypsy / Irish Traveller population has long been problematic and widely reported not to be accurately known[52], though estimated at between 200,000 & 300,000 (the latter 0.5% of the population) by several sources. Many JSNAs have used the caravan count[53] and converted this into either households or individuals using multipliers but this gives only an approximate estimate that excludes the population in bricks and mortar housing.

However, the inclusion of 'Gypsy or Irish Traveller' as a category under the 'White' label in the England and Wales 2011 Census (and similar categorisation in Scotland and Northern Ireland) has altered this situation (following release of the ethnic group data in November 2012). For Gypsy, Roma & Traveller sites the 2011 Census HQ liaised with their representative groups and with local authorities to develop suitable procedures. Coordinators made prior contact with local authority Gypsy liaison managers who were able to establish contact points on site. Hand delivery and collection of forms and use of special enumerators is reported to have worked well[54]. Hitherto, this group has been concealed in categories like 'White Irish' and 'Any other White background'. The data is currently available for a number of tiers of census geography, including local authorities. A total of 57,680 Gypsies or Irish Travellers were enumerated across England and Wales, including 14,542 in the South East, 8,196 in London, and 8,165 in the East regions. These figures are generally lower than in many accommodation needs assessments and will, no doubt, be subject to quality review by ONS. Their accuracy has been questioned by community organisations and investigators[55]. Recent ONS releases have differentiated Gypsies / Irish Travellers by accommodation type: whole house or bungalow was the most common type of accommodation for respondents who identified as Gypsy or Irish Traveller, at 61 per cent (84 per cent for England and Wales as a whole), followed by caravan or other mobile or temporary structure at 24 per cent (0.3 per cent for England

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[52] Communities & Local Government. *Progress report by the ministerial working group on tackling inequalities experienced by Gypsies and Travellers*. London: Department of Communities and Local Government, 2012 (April).

[53] Office of the Deputy Prime Minister. *Counting Gypsies and Travellers: A review of the Gypsy Caravan Count System. Housing Research Summary 203*. London: ODPM, 2003.

[54] ONS. *2011 Census Evaluation Report: 2011 Census Field Operations*. July 2012.

[55] Irish Traveller Movement in Britain. *Gypsy and Traveller population in England and the 2011 Census*. London: ITMB, 2013 (August); Dar O, Gobin M, Hogarth S, Lane C, Ramsay M. Mapping the Gypsy Traveller community in England: what we know about their health service provision and childhood immunization uptake. *Journal of Public Health* 2013; 35(3): 404-412.

and Wales as a whole)[56]. Further breakdown of the 'Gypsy or Irish Traveller' count is available by country of birth and national identity: Gypsy or Irish Travellers born in non-UK EU countries was double the proportion for England and Wales as a whole, 8 per cent compared to 4 per cent. The majority of people who identified as Gypsy or Irish Traveller identified with an English only national identity (66 per cent). The census variable relating to address one year ago when released will provide a measure of residential mobility/turnover.

The 2011 Census provides the following measures of *generic health status*:

- *General health*: Age-standardised rates/ratios of very good/good/fair/bad/very bad health
- *Limiting long-term illness*: Age-standardised rates/ratios of limiting long-term illness (limited a lot, limited a little, & not limited). Gypsy or Irish Traveller men and women had the highest ratios of limiting long-term illness of all ethnic groups (1.99 and 1.93, respectively), almost twice the White British illness ratio[57].
- *Long-term sick or disabled*: Age standardised rates/ratios, population aged 16 or over not working or on a government sponsored training scheme

Adoption of 2011 Census Categorisation

So far the adoption of the England and Wales 2011 Census ethnic group classification across government has been very limited and has not met the CLG's expectation that '…inclusion of such a category in the 2011 Census will provide a clear signal to other bodies, including local authorities and the NHS as well as other public bodies to review their ethnic monitoring systems to include "Gypsy or Irish Traveller" as a category, and use the resulting data for better planning and commissioning'[58]. Unlike the 2001 Census, there has been no DSCN mandating a change to the 2011 classification in NHS/Department of Health and other government datasets. However, ISD Scotland has adopted the 2011 classification in the Scotland Data Dictionary and ONS Harmonised Concepts and Questions for Social Data Sources for Ethnic Group include 'Gypsy or Irish Traveller'[59]. This matter was recently the subject of a parliamentary question in the House of Lords[60].

6.2 The capture of the Gypsy / Irish Traveller population in routine health and social care datasets

6.2.1 Use of GP/primary care services: There is no comprehensive data source on how many GP practices/PCTs use ethnic coding that encompasses 'Gypsy /Irish Traveller' in their registration of patient ethnic group. Some PCTs may be using Gypsy / Roma categorisation

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[56] ONS. *What does the 2011 Census tell us about the characteristics of Gypsy or Irish Travellers in England and Wales*. London: ONS, 2014 (21 January). http://www.ons.gov.uk/ons/dcp171776_349352.pdf

[57] Bécares L. *Which ethnic groups have the poorest health? Ethnic health inequalities 1991 to 2011*. Manchester: ESRC Centre on Dynamics of Ethnicity, 2013 (October).

[58] CLG. *Progress Report on Gypsy and Traveller Policy*. Department of CLG, 2009 (July).

[59] See: http: http://surveynet.ac.uk/sqb/harmonisation/ethniceng.asp.

[60] Lord Avebury. Gypsies and Travellers. *Lords Hansard* [HL4018]. Written Answers 8 January 2013.

in ethnicity data collection. A primary care service framework for Gypsy and Traveller communities was issued by NHS Primary Care Contracting in May 2009[61]: this recommended the recording of the ethnic status of Gypsies and Travellers using Read Codes. The guidelines also suggest the building of an information base on Gypsy Travellers following the good practice example of the Leeds Race Equality Council Baseline Census 2004-2005 in enumerating this population[62]. However, it is known that Gypsies / Irish Travellers have low rates of GP registration: 16% were not registered compared with 1% of comparators in the Parry *et al.* (2004) study and the exclusion of Gypsy/Irish Traveller coding in the 2001 Census ethnic group classification may have limited the use of this coding[63].

6.2.2   *Use of hospital services:*

There is currently no recording of Gypsy or Irish Traveller in the **HES Datasets** (HES Admitted Patient Dataset; HES Outpatient Dataset; A & E HES Dataset; PROMS Dataset; Adult Critical Care Dataset; and HES-ONS Linked Mortality Dataset). The ethnic coding currently used is that for the 2001 Census, introduced to these datasets during 2001-02. This is a major drawback with respect to Gypsy or Irish Traveller Health, given the evidence on maternal morbidity and mortality. The HES Admitted Patient Dataset includes deaths that take place in hospital (hospital case fatalities), including mothers who die giving birth. This dataset is the source for Maternity Statistics in England and these therefore omit Gypsy or Irish Traveller. The Department of Health has acknowledged that 'national data are not collected about … the services they [Gypsies and Travellers] receive'. This situation could be remedied by the issue of a DSCN mandating use of the 2011 Census categorisation. Though 'Gypsy or Irish Traveller' is not a standard reporting category, some hospital trusts include this category on their confidential patient data forms (e.g. East Kent Hospitals University NHS Trust[64]).

6.2.3   *Sources on birth outcomes:*

<u>*Birth registrations*</u> do not include ethnic group. *NHS Birth Notification records* are ethnically coded, and *linked birth registrations/NHS birth notifications/death*

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[61]

http://www.pcc.nhs.uk/uploads/primary_care_service_frameworks/2009/ehrg_gypsies_and_travellers_pcsf_190 509.pdf

[62] Leeds Baseline Census 2004-2005. http://www.grtleeds.co.uk/information/census.html

[63] The findings of Matthew Brindley's work for the Irish Traveller Movement in Britain - which addresses the lack of national data on the health status of Gypsies and Travellers - is presented in the following report: Irish Traveller Movement in Britain. *Inclusion and ethnic monitoring of Gypsies and Travellers in the NHS.* London: Irish Traveller Movement in Britain, 2012 (November). Based on responses to freedom of information requests sent to 146 PCT's, they confirm concerns about the exclusion of Gypsies and Travellers in the NHS's routine monitoring and poor coverage in JSNAs.

[64] www.ekhuft.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=213078

registrations for babies who died before 1ˢᵗ birthday (providing information on live births, stillbirths, neonatal deaths, infant mortality, pre-term births, and small for gestational age babies) are, consequently, linked to such coding. However, the ethnic coding used in the NN4B dataset[65] is for the 2001 Census (thus omitting Gypsies and Travellers). Moreover, for other ethnic groups, while ethnicity data in England and Wales is now available for births through this record linkage, it is missing for around 10% of records, with much higher levels in some local authorities, e.g. 98% in Leicester. Thus, sources on birth outcomes represent a major gap.

6.2.4   *Maternal morbidity and mortality:*

The *UK Obstetric Surveillance System (UKOSS)* also uses the 2001 Census classification, therefore omitting Gypsy or Irish Traveller[66]. Again, Gypsy/Irish Traveller coding is needed to monitor maternal morbidity/mortality.

The *Confidential Enquiry into Maternal and Child Health* (CEMCH) (which became the Centre for Maternal and Child Enquiries [CMACE] from 1 July 2009) also lacks utility for the Gypsy/ Irish Traveller population. Maternal death notifications use 2001 Census ethnic coding and therefore exclude Gypsies or Irish Travellers. This is also the case with other sources that might be utilised, including coroners' records, SHA notifications, and, as noted, hospital records. The most recent (eighth) report of the confidential enquiries into maternal deaths in the UK by CMACE[67] and NHS London's review of maternal deaths in London[68] makes no mention of 'Gypsy', 'Roma', or 'Irish Traveller': these groups are concealed in the reporting category 'White'. Some earlier CEMCH reports do mention Gypsies / Travellers[69].

In the *Maternity Services Secondary Uses Dataset* the mother's demographics include an 'Accommodation Type (mother at booking)' field, the coding for which includes: 'Traveller'. It has not been possible to assess the utility of this coding in reported statistics from the dataset.

Thus, sources on maternal morbidity/mortality represent a major gap.

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[65] See specification for NN4B dataset:
http://www.connectingforhealth.nhs.uk/industry/docs/nn4b/nn4bdataset.pdf
[66] See all UKOSS Data Collection Forms at: https://www.npeu.ox.ac.uk/ukoss/dcf
[67] Centre for Maternal and Child Enquiries (CMACE). *Saving Mothers' Lives: reviewing maternal deaths to make motherhood safer: 2006-08.* The Eighth Report on Confidential Enquiries into Maternal Deaths in the United Kingdom. *British Journal of Obstetrics and Gynaecology (BCOG)* 2011; 118 (Suppl.1): 1-203.
[68] NHS London. *A review of maternal deaths in London, January 2009-June 2010.* London: NHS London, 2011.
[69] Royal College of Gynaecologists. *Why mothers die. 1997-99: The confidential enquiries into maternal deaths in the United Kingdom.* London: RCOG Press, 2001.

6.2.5 *Childhood immunisations:*

Information on childhood immunisation coverage at ages 1, 2 and 5 is collected through the *Cover of Vaccination Evaluated Rapidly (COVER) data collection* from Child Health Information Systems (CHISs) for PCTs. This source does not request data on ethnic group[70] and there is no mention of this demographic in the *NHS Immunisation Statistics England* bulletins. Thus, no routine information is available on Gypsies or Irish Travellers. Information about immunisation of children aged 13-18 years receiving a reinforcing dose of tetanus, diphtheria, and polio (Td/IPV) & MMR & the BCG Programme for all persons is collected on *the KC50 return* from Trusts providing immunisation services. There is no recording of ethnic group on the KC50 form[71]. The omission of ethnic coding on these sources does seem surprising: Aspinall (2006)[72] has argued:

> These new findings - together with obligations in the Race Relations (Amendment) Act 2000 - present a case for the ethnic coding of the COVER (Cover of Vaccination Evaluated Rapidly) data collected as a central return. The NHS has indicated that, as a general rule, all central return submissions relating to patients and the services provided to patients should include consideration of the case for collecting ethnic origin information (and that this should be the norm in cases where personal profile information such as age and gender is collected). With reference to the national contexts referred to by Crampton and Carr (2006), the National Immunization Survey in the USA includes data on race (Smith *et al.*, 2005) and the data requirements for the National Immunisation Register, set up in New Zealand in 2004, incorporate ethnic group.

The Millennium Cohort Study (MCH) provides an alternative source on *immunisation*[73] of children by ethnic group. While the MCH's ethnic coding includes 'Irish Traveller', 'Traveller', and 'Gypsy/Romany' coding and the MCH collects detailed data on the immunisation of the Cohort child, this source lacks utility for Gypsies / Travellers. While sample sizes for this question vary from around 16,000-18,000 mothers of cohort

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[70] For a copy of the COVER Data Collection Form, see:
http://www.ic.nhs.uk/webfiles/publications/003_Health_Lifestyles/Immunisation%20Stats%202010-11/Immunisations_Bulletin_2010_11_v1_3.pdf (see pp. 86-87).
[71] For a copy of the KC50 form, see:
http://www.ic.nhs.uk/webfiles/publications/003_Health_Lifestyles/Immunisation%20Stats%202010-11/Immunisations_Bulletin_2010_11_v1_3.pdf (see pp. 80-81).

[72] Aspinall PJ. Need for routine collection and reporting of ethnicity in immunisation statistics. *British Medical Journal* (20 June 2006). http://www.bmj.com/cgi/eletters/332/7553/1312#136003

[73] See for an example of immunisation status by ethnic group: Samad L, Tate AR, Dezateux C, Peckham C, Butler N, and Bedford H.. Differences in risk factors for partial and no immunisation in the first year of life: prospective cohort study. *BMJ* 2006; 332: 1312-1313.

children (that is, all ethnic groups)[74], the numbers of Gypsy / Irish Traveller mothers are negligible[75].

Thus, sources on childhood immunisations represent a major gap. In a recent analysis of 135 PCTs providing questionnaire response data, only 88 (65.2%) reported having knowledge of caravan sites within the PCT boundaries. Of these 88 PCTs, only 20-22 (25%) were able to estimate the coverage of the polio 3rd dose and MMR 1st dose amongst Gypsy/Traveller children[76].

6.2.6 *Infectious diseases*

The main source of information on infectious diseases is the *disease notification* system. The Health Protection (Notification) Regulations 2010 requires a specified list of certain diseases and infections to be notified to the local Health Protection Unit (including measles, mumps and whooping cough). The notification form template[77] has a field for 'ethnicity' in the index case details (unprompted by an ethnic group classification) but those who have attempted to use it to identify Gypsies or Irish Travellers have found it incomplete or of poor quality. For example, Maduma-Butsche & McCarthy (2012) have noted: 'Surveillance has not routinely or reliably identified whether cases of disease are members of the Gypsy-Traveller communities'[78]. Thus, sources on infectious diseases represent a major gap.

6.2.7 *Community Care Services*

The main routine data source on community care services is the *Referrals, Assessments and Packages of Care collection*. This dataset on community care for adults is one of the few NHS Information Centre's datasets that has ethnic coding for Gypsies/Travellers. From 2009-10 the ethnic categories 'Gypsy/Roma' and 'Traveller of Irish heritage' were added to RAP proformas A6 (number of new clients for whom an assessment was completed in the period, by age group, ethnicity, and known or anticipated sequel to assessment) and P4 (number of clients receiving services provided or commissioned by Councils with Adult Social Service Responsibilities [CASSR] during the period, by age group and ethnicity, cross-tabulated with service

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[74] Dex S, Joshi H. *Millennium Cohort Study. First Survey: A User's Guide to Initial Findings*. London, Centre for Longitudinal Studies, 2004 (July).

[75] Indeed, there is only one case in Northern Ireland where the child is self-reported as being Gypsy/Romany/Traveller/Irish Traveller. This one case was picked up as 'Other' and coded. One reason why the number is so low could be that the sample was drawn from the Child Benefit records with an opt out and it may be that this group are more likely to either opt out from such surveys and/or less likely to take up this Benefit. I am grateful to Jon Johnson, Senior Database Manager, Centre for Longitudinal Studies, for this information.

[76] Dar et al., 2013, *op. cit.*

[77] See form template*: www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1270616536780

[78] Maduma-Butsche & McCarthy (2012)

type and primary client type) under the 'White' heading[79]. Data has recently been released for the 2011-12 collection year for England. The numbers in the Gypsy/Traveller categories are relatively low: 50 Travellers of Irish Heritage and 80 Gypsy/Roma new clients for whom an assessment was completed, with a breakdown by age group & known or anticipated sequel to assessment; 90 Travellers of Irish Heritage and 120 Gypsy/Roma clients receiving services provided or commissioned by the CASSR, broken down by community-based services, residential care, and nursing care; and 30 Travellers of Irish Heritage and 40 Gypsy/Roma clients receiving self-directed support and/or direct payments provided or commissioned by the CASSR[80].

6.2.8 Children in need

The main routine data collection is _Children Looked After_. The codes 'Gypsy/Roma' and 'Traveller of Irish Heritage' were added to the Children Looked After statistics for the first time in 2009. The most recent statistical releases for the years ending 31st March 2009 & 2010 show small numbers of children being looked after at the end of the years[81]: Traveller of Irish Heritage: 2009 (20); 2010 (30); Gypsy/Roma: 2009 (30); 2010 (50). The number of children who *started* to be looked after during 2009 and 2010 were, respectively, Traveller of Irish Heritage: 20, 20; Gypsy/Roma: 30, 60.

6.3 Other sources on Gypsy / Irish Traveller Health to Populate Gaps

The gaps in routine information sources on Gypsy / Irish Traveller health are notable. These gaps occur in the areas of morbidity / mortality where Gypsies / Irish Travellers have enhanced risks or elevated rates. There are, however, some sources that help to populate the gaps.

6.3.1 Child Death Review Process/Child Death Overview Panels

It may be possible to address the lack of data on birth outcomes (notably, infant mortality) for Gypsies / Irish Travellers through _the Child Death Review Process/Child Death Overview Panels_. *Working Together to Safeguard Children* (Chapter 7) sets out the procedures to be followed when a child dies. There are two interrelated processes for reviewing child deaths (either of which can trigger a serious

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[79] Letter: NHS Information Centre to Information contacts in England. 30 September 2009. Reporting of Adult Social Services Statistical Data to the NHS Information Centre:
http://www.ic.nhs.uk/webfiles/Services/Social%20care/Collections%200910/LA%20Letter%20Sep%202009.pdf

[80]   http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-social-services-activity-england--2011-12

[81] http://www.education.gov.uk/rsgateway/DB/SFR/s000960/sfr27-2010v2.pdf

case review): 1. A rapid response by a group of key professionals who come together for the purpose of enquiring into and evaluating each unexpected death of a child; 2. An overview of all child deaths (under 18 years) in the local safeguarding children board (LSCB) area(s), undertaken by a panel. Child death overview panels (CDOPs) are responsible for reviewing information on all child deaths, and are accountable to the LSCB chair. CDOPs may serve more than one LSCB. Child death review processes became mandatory in April 2008, though LSCBs have been able to implement these functions since April 2006.

The Department for Children, Schools and Families model proforma for 'Notification of Child Death' includes 'Traveller of Irish Heritage' and 'Gypsy/Roma' in its ethnic group categorisation[82]. A rapid review of the CDOP protocols and 'Notification of Child Death' forms used by local authorities reveals that many include this coding (Berkshire; Cambridgeshire & Peterborough; Hampshire, Isle of Wight, Portsmouth and Southampton; Tees; Hampshire; Manchester; Bolton; and Milton Keynes, for example); others use the 2011 Census category (Gypsy or Irish Traveller) (Bedfordshire & Luton; Lancashire and Blackburn with Darwen; Medway; Bury, Rochdale and Oldham; Sheffield; Wandsworth; Telford, Wrekin & Shropshire; Dorset; Bromley; Staffordshire & Stoke on Trent; and South of Tyne and Wearside, for example). Many of the Safeguarding Children Board Annual Reports contain data for Gypsies/Travellers.

6.3.2 Government health and social surveys

Few government health and social surveys have samples large enough to capture Gypsies / Travellers (searches have been undertaken on the ESDS databases using 'variable search' and also on the content of questionnaires in the Survey Question Bank). The largest of these, the _Integrated Household Survey_, contains a question on ethnic group (including 'Gypsy or Irish Traveller') and has a small question set on health, smoking, and subjective well-being:

- General health (very good, good, fair, bad, very bad)
- Long-standing illness, disability or infirmity
- Illness or disability that limits activities
- Ever smoked a cigarette, cigar or pipe
- Current cigarette smoker
- Satisfaction with life nowadays
- Things you do in life are worthwhile
- How happy felt yesterday
- How anxious felt yesterday

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[82] See: http://childdeath.ocbmedia.com/public_docs/Proforma%20-%20Form%20A%20-%20Notification%20of%20Child%20Death.pdf

However, only 45 cases of 'Gypsy or Irish Traveller' were reported in the July 2010-June 2011 data[83], 81 in the year January-December 2011, and 64 in the year January-December 2012, so around three or four years of pooled data may be needed to obtain a useable count of around 250. The 'Gypsy or Irish Traveller' variable was added to the IHS in 2011 (via the Labour Force Survey where it was first introduced in 2011).

However, the 2012 GP Patient Survey does contain a usable sample[84]. Amongst its achieved sample of 966,985 persons, a total of 334 Gypsies/Irish Travellers were included. The GP Patient Survey contains modules on 'Accessing Your GP Services', 'Making an Appointment', 'Waiting Times', 'Last GP Appointment', 'Last Nurse Appointment', 'Opening Hours', 'Overall Experience', 'Managing Your Health', 'Your State of Health Today', 'Out of Hours', NHS Dentistry', and 'Some Questions about You'. A minor drawback is that sampling is based on those registered with GPs.

The UK has not had a dedicated Gypsy / Irish Traveller health survey like Ireland. The All-Ireland Traveller Health Study (AITHS) provided information on the Irish Traveller population, mortality, and health data. Given the magnitude of the gaps in routine data sources, this may be an option for the future. The data on where Gypsies / Irish Travellers live in the 2011 Census (caravans and bricks and mortar) would provide the basis for developing a sampling design, though with the possibility of under-enumeration.

6.3.3 *Use of unique postcode/s for authorised Gypsy/Irish Traveller sites*

Authorised sites for Gypsies / Travellers (local authority and private) are assigned unique postcodes. These can be accessed on most local authority websites[85], many of which provide a map of the site/s, the number of pitches, and the postcode/s (see, for example, East Sussex[86]). With respect to unofficial encampments (around one quarter of caravans in the annual caravan count are on unauthorised sites), it appears not to be general practice to assign postcodes, though in the case of one site bought by Gypsies/Travellers who were seeking planning permission, press reports show that in a crown court case Fylde Council was instructed to 'use its best endeavours' to facilitate obtaining a postcode[87].

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[83]

http://www.openmetadata.org/surveycatalog/index.php/catalog/6809/search?vk=gypsy+or+irish+traveller&search=Search&vf%5B%5D=name&vf%5B%5D=labl&vf%5B%5D=qstn&vf%5B%5D=catgry

[84] http://www.gp-patient.co.uk/questionnaires/

[85] <local.direct.gov.uk/LDGRedirect/index.jsp?LGSL=655&LGIL=8> also provides a point of access to site information.

[86] See: http://www.eastsussex.gov.uk/community/migrants/travellers/travellers.htm

[87] http://www.dailymail.co.uk/news/article-1257169/Anger-judge-awards-illegal-travellers-camp-postcode--despite-opposition-local-council-residents.html; http://www.thesun.co.uk/sol/homepage/news/2888942/Its-a-pestcode-judge-orders-official-address-for-gipsy-eyesore.html.

Postcodes for official sites can then be linked to routine health datasets (nearly all of which contain the postcode of the person's residential address). Clearly, this method is only of utility for Gypsies/Travellers living on authorised sites (to the exclusion of those living in unofficial encampments, at roadside sites, and in permanent housing). In some cases this divide in housing circumstances may mirror different communities: in Sheffield, for example, Slovak Roma are found in houses and Irish Travellers on sites. Moreover, using census counts as denominators may be problematic with this approach. Nevertheless, the analysis of postcodes has been used in a number of studies and offers a promising approach in the JSNA process:

▪ Newark & Sherwood PCT have used this approach via a Specialist Registrar in Public Health[88]: 'This is the first time that Travellers health needs have been systematically assessed. By using a unique postcode identifier, information pertaining to Travellers was obtained from the routine health statistics. This was then compared with the district average and other local information with various agencies'. By such means robust data (with confidence intervals) was reported for the postcode and reference PCT population: mortality rate; mortality rate for smoking-related conditions; emergency hospital admissions; and uptake of: MMR and meningitis immunisations, breast screening, & cervical screening. The case study was winner in the NHS in Trent Diversity Award, 2005.

▪ A study of domestic abuse in the Gypsy Traveller community in Cardiff also uses this method[89]. Since 2005, the Cardiff Women's Safety Unit (WSU) have been recording all their referrals from the Police Domestic Abuse Unit, health visitors, A&E departments and various other health/social support services on an electronic database. The Gypsy-Traveller community in Cardiff is clustered at two caravan sites, each with a unique postcode. All electronic records were retrieved with postcode details and an attempt was made to identify referrals from the caravan sites based on postcode. 5158 records were retrieved ranging over 4.5 years. However, 2696 records had no postcode available, limiting the utility of this method, that is, only 47% had a postcode recorded. None were for the two sites.

6.3.4 *Use of unique surnames to identify Irish travellers*

Only one study has been identified that uses this approach (Naughton, Brooks & Webb 2010)[90]. As well as use of dedicated postcodes to identify domestic abuse cases, a search was made of the 5158 records retrieved using the 35 most common Irish Traveller surnames[91]. Although name recognition algorithms have obvious

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[88] http://www.tin.nhs.uk/event-calendars/success-2005/category-definitions/working-partnerships/gypsy-travellers-newark/
[89] Naughton J, Brooks R, Webb E. Domestic abuse in the Gypsy Traveller community of Cardiff. *Welsh Paed J* 2010; 34: 45. The paper was Professor DP Davies and Professor JR Sibert prize winner, 2010.
[90] Ibid., Naughton, Brooks & Webb 2010.
[91] Lalor B. *The Encyclopaedia of Ireland*. Gill & Macmillan; 2003; Shuinear S. Traveller surnames: existing lists amalgamated by Sinéad ní Shuinéar, Historical Resources for Research – into the social,

limitations, the search based on common Irish Traveller surnames revealed significant findings: 'Even though these surnames are disseminated throughout the general population, many are unique to this community, whilst mainstream surnames are rare amongst Irish Travellers'. The proportion of common Irish Traveller surname referrals was disproportionately high (2.79%) and 29-fold greater than the proportion of the Cardiff Irish Traveller population (0.095%). In addition, the geographical distribution of reporting of domestic abuse from people with these surnames was highest from the CF3 postcode sector (26%) which is the vicinity of the caravan sites (CF24 2RX & CF3 2EE). Moreover, this area has the lowest proportion of ethnically Irish people in Cardiff (0.6% vs 0.9%). The investigators ask whether a small population of Irish Travellers might account for a large amount of referrals.

No other studies have been identified and this approach may have its limitations[92].

6.4   Sources on the determinants of health and health inequalities

6.4.1   Gypsy and Traveller Accommodation Needs Assessments

There is a statutory duty on local and regional authorities under the Housing Act 2004 and Planning Act 2004 to assess Gypsy and Traveller accommodation needs and develop strategies to meet those needs. Guidance on accommodation needs assessments was provided by CLG in October 2007[93]. The assessment of Gypsy and Traveller accommodation needs when carrying out a periodical review of housing needs under section 8 of the Housing Act 1985 is a statutory requirement under section 225 of the Housing Act 2004 & came into force on 2 January 2007. Local authorities may also be required, under section 87 of the Local Government Act 2003 (as amended), to produce a strategy that addresses the need identified, including that of Gypsies and Travellers. The assessment and the strategy will need to be informed by a full understanding of their accommodation needs. A Gypsy and Traveller Accommodation Needs Assessment will be required either as part of a Strategic Housing Market Assessment in respect of the local community generally, or separately where a Strategic Housing Market Assessment is not being conducted at that time. The guidance talks about 'a robust and credible evidence base', likely to

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economic and cultural history of the Irish travellers: HEA funded report, 2010; *Report of the Commission on Itinerancy*. The Stationery Office, Dublin. 1963.

[92] Advice was taken from Dr Pablo Mateos, UCL, an expert on ethnicity and the use of names, on the utility of this approach.. I am grateful for his view that there could be some surnames that are highly represented within the Irish Traveller group, in terms of relative frequency, because of their presumably high rates of in-marriage. However, unless the rest of the population moved away from such names, it is doubtful that those names could unequivocally identify Irish Travellers within the British Isles. If use of a distinctive language had created unique inheritable surnames within the group in the last 500-700 years or so, the approach might have value. Clearly, further investigation is needed before the method can be recommended.

[93] Department of Communities & Local Government. *Gypsy and Traveller Accommodation Needs Assessments. Guidance*. London: Department of Communities & Local Government, 2007 (October).

encompass both an analysis of existing data sources and the conducting of a specialist survey. DWP has indicated that by 2010 the vast majority of local authorities had completed these assessments. CLG has also stated that information from the first round of assessments 'provide an excellent evidence base for those planning for the accommodation needs of Gypsies and Travellers'. According to the guidance, such sources are likely to include:

- The number of Gypsy and Traveller caravans and type of site on which they are located recorded by the local authority via the Gypsy and Traveller caravan count every January and July. Until January 2005, the caravan count also recorded numbers of families. This data is publicly available on the Communities and Local Government website.

- Information should also be available from local authority site management records (length of licenses, pitch turnover, site waiting lists, transfers, etc.);

- Information relating to private authorised sites;

- Local authority data on unauthorised encampments and unauthorised developments in their area (Gypsies and Travellers on unauthorised developments can be identified via the appropriate local authority planning department);

- A local authority may also have additional sources of data about local Gypsy and Traveller populations, via service providers, such as health workers, Supporting People staff, and the Traveller Education Service (TES) (the latter will have information on Gypsy and Traveller pupil numbers via the Pupil Level Annual School Census);

- Gypsy Liaison Officers and others working with the community may have detailed records of encampments, which are useful in assessing the need for transit provision, and more personal knowledge of Gypsy and Traveller communities;

- Local authority housing records are unlikely to identify Gypsies & Travellers in bricks & mortar housing, except where ethnic monitoring categories include these groups (even then, there may be an undercount because of reluctance to identify in these categories). Similarly, housing waiting lists are unlikely to identify Gypsies and Travellers as a BME category unless included as monitoring categories;

- Data may be available from specialist surveys and/or qualitative research (the CLG guidance provides a topic list for a specialist survey).

6.4.2 *Annual School Census*

The Census is a statutory return for all maintained nursery, primary, and secondary schools, special schools, academies, and city technology colleges in England (similar censuses are undertaken in Wales & Scotland). The data collected includes pupil

identifiers (name, gender, date of birth), pupil characteristics (such as ethnicity, language, disability), where the pupil lives during term-time, exclusions, and attendance/absences. Ethnic category coding includes 'Travellers of Irish heritage' and 'Gypsy/Roma'. The census information is linked to the National Pupil Database which contains data on educational attainment. Some adjustment may be needed to take account of dually registered children (i.e. children registered in multiple schools in different parts of England)[94].

6.4.3 Local sources relating to particular projects

Gypsy / Irish Traveller JSNAs have frequently exploited such sources. There are now a great many local Gypsy / Irish Traveller projects, including those that contributed to the *Pacesetters Programme*, that have generated useful data on health status and use of health services.

6.5 Major gaps

The most effective strategy to capture Gypsies/Irish Travellers in health and social care datasets and data collections would be to seek sponsorship for a Dataset Change Notice mandating the use of the 2011 Census Ethnic Group classification in all such data collections. This happened after the 2001 Census but not after that for 2011. The Census categories and classifications are authoritative as they have been derived through processes of extensive testing, including cognitive research, small-scale tests, and large-scale trials. Also, census data provides the denominators for the calculation of rates and ratios. Post-census evaluation and validation reports and the census counts may throw light on how successfully Gypsies / Irish Travellers have been enumerated. The current failure to adopt the 2011 Census ethnic group question leaves Gypsies / Travellers in the anomalous position of having been defined as an ethnic/racial group within the meanings of the Race Relations Acts and 2010 Equality Act, and therefore fully protected by anti-discrimination provisions, yet outwith most data collection systems, including the five monitored hate crime strands recorded by the police. Only one or two data collections have adopted the 2011 ethnic group categories (including the Prison Information System, P-Nomis).

Notable gaps include maternal morbidity/mortality, birth outcomes, and childhood immunisation. Also, there is no data on suicides in the Gypsy and Traveller community (no data is collected on ethnic group at death registration or on coroners' records). In Ireland survey data and linkage to mortality records has provided this information. Case study research into suicides may represent the best approach at present.

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[94] Dar *et al*., 2013, *op cit.*

7. USE OF ROUTINE AND OTHER DATA SOURCES FOR HOMELESS PEOPLE

This section focuses on data sources that provide comprehensive and robust denominator data for the homeless population and the capture of the homeless population in routine datasets.

7.1 Comprehensive denominator data: 2011 Census

There is no comprehensive source of denominator data on the homeless population as a whole or its various subgroups. One recent source is the 2011 Census. Homeless persons - rough sleepers and those in hostels for the homeless - were counted in the 2011 Census, as they had been in the 2001 Census. In the 2001 Census initial liaison took place with the Rough Sleepers Unit of the (then) Department of the Environment, Transport and Regions to explore the potential for them to assist and advise in counting persons sleeping rough. Some information on particular areas where there were known to be persons sleeping rough was obtained through this contact. Additionally every local authority within England and Wales was contacted for geographical information on persons sleeping rough and contact was made with organisations such as the National Homeless Alliance and Shelter from which volunteers were sought to help conduct the enumeration. The count of rough sleepers was held on census night between 22:00 hours and 06:00 hours the following morning. For each location containing one or more rough sleepers, the enumerators completed a communal establishment questionnaire, which had a specific category for rough sleepers and which provided an address to link the individuals to. The enumerators then either asked rough sleepers to complete their own individual questionnaire, or tried to gather basic demographic information on the individual's behalf. The total number of rough sleepers recorded in the 2001 Census in England and Wales was 938.

For the 2011 Census ONS concluded through discussions with many organisations that it would be feasible to identify and count rough sleepers at day centres for the homeless; other homeless people could be enumerated at homeless hostels and similar accommodation. Co-ordinators made prior contact with day centres for the homeless to build relationships and make arrangements for the enumeration. The enumeration of rough sleepers is reported to have achieved good results, the basic statistics collected being in line with the statutory autumn 2010 street counts and, indeed, in some areas were higher[95] (local authorities are required to conduct their own annual counts or estimates of sleepers that are reported to Communities & Local Government & ONS learnt how they carried out their counts to identify successful procedures that could be used or modified). Hostels or night shelters which had homeless people staying were enumerated as Communal Establishments (CEs). CE managers completed a questionnaire containing basic questions on the accommodation type and including a headcount of all visitors staying there on census night. Anyone staying at the establishment who had no usual residence elsewhere was asked to complete an

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[95] ONS. *2011 Census Evaluation Report: 2011 Census Field Operations*. July 2012.

individual questionnaire, including any non-UK residents who intended to stay in the country for three months or more. The individual questionnaire contains the complete set of census questions that would normally be completed by household residents.

These data have now been released by ONS. 1,575 'hostels or other temporary shelters for the homeless' in England and Wales reported 21,574 persons in those establishments. A rough sleeper count of 208 persons has also been released. Though standard tables do not appear to provide health data for the above categories, it may be possible through the table commissioning process to obtain age-standardised measures of limiting long-term illness and general health.

The Office of the Chief Analyst has expressed concern that not all vulnerable homeless people may be captured by the Census[96]. Moreover, the Census provides a 'snapshot' measure (the number of people sleeping rough, in the hostel system, etc., at any one time), whereas a 'stock' and 'flow' measure may be more useful (the number of people who have, at any point in say the last year, slept rough or lived in the hostel system and the number of first time rough sleepers). Clearly, Census counts of rough sleepers can be compared with the local authority annual street counts (see below). With respect to those homeless people in the hostel system, census counts could be set against (i) the Homeless Link Homeless UK Database[97] which gives estimates of first- and second-stage homeless hostel bed-spaces and (ii) Supporting People data ('single homeless with support needs' & 'rough sleeper', though other categories may be important but lack specificity, e.g. 'young people at risk'), available at the local authority level. It is much more difficult to estimate 'flow' numbers, though the Office of the Chief Analyst attempts some estimates[98].

7.2 The capture of the homeless population in routine health and social care datasets

7.2.1 Use of hospital services:

Given the high use of secondary services, the greater likelihood of being admitted as emergency admissions, and significantly longer length of stays, this is a priority area. However, there is currently only limited recording of homelessness in the *Hospital Episode Statistics (HES) Datasets* (Admitted Patient Dataset; Outpatient Dataset; A & E Dataset; PROMS Dataset; Adult Critical Care Dataset; and HES-ONS Linked Mortality Dataset). The only relevant coding that provides a point of access to homelessness is the

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[96]
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114 369.pdf
[97] Survey of Needs and Provision (SNAP), Homeless Link, 2012. Accessed at:
http://homeless.org.uk/sites/default/files/SNAP2012%20fullreport.pdf
[98]
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114 369.pdf

'zz99 3VZ" 'no fixed abode' code for the 'Postcode of Patient' field[99]. 'No fixed abode' is also a value in the 'Government Office Region of residence' field. The NFA coding is widely regarded as unsatisfactory. For example, some of the 'no fixed abode' population may give the postcode of their homeless hostel, shelter, or other temporary accommodation or of a friend or relative. The coding may also capture people who are not homeless but want to conceal their true address because of the sensitivity of their treatment, if for example, that is for a sexually transmitted infection, drug misuse, domestic violence, etc. The NFA coding may also appear inappropriately as a result of poor data quality coding practices. St Mungo's & Homeless Link have described the coding as 'inconsistent' and, therefore, '…difficult to track outcomes' and the Office of the Chief Analyst's report into Homeless People in 2010 as 'not a perfect indicator of homelessness'.

'The usual place of residence, including no fixed abode' category included in the 'Source of Admission' and 'Destination on discharge' fields is uninformative as this generic coding does not indicate housing need. This is a major drawback as, with informative coding on homelessness in the 'Source of Admission' field, planning could start at the point of admission on arrangements for discharge. The 'no fixed abode' coding is also used in the Outpatient Dataset and the A & E Dataset 'Postcode of Patient' field[100]. The A & E Dataset also has a two-character A & E diagnosis field that includes the code: 37 = social problems (including chronic alcoholism and homelessness). However, there is no coding in the A & E dataset's 'Attendance Disposal' (including discharge) field that relates to homelessness, where the 4-hour turnaround time frequently limits scope for action. Much of the data reported for the 'no fixed abode' postcode is for episodes though algorithms can be used to allocate episodes to persons.

Nevertheless, the data has been used to investigate a range of issues related to homeless people:

- *The extent to which homeless people are registered with a GP*: The Slough JSNA (2011-12)[101] used the zz99 3VZ code to examine GP registration. Around half the cases had an established general practice code, lower than the national audit finding which identified that 86% of those classified as homeless are registered with a GP.

- *The use of hospital & A & E services*: Using data from specialist general practices, the Office of the Chief Analyst reported that A & E attendances amongst the homeless were 5 times the local average & hospital admissions were 3.2 times the local

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[99] This is different from ZZ99 3WZ = postcode not stated/specified. ZZ99 3VZ should, there, not include address unknown. See: Post code description from NHS Data Dictionary - http://www.datadictionary.nhs.uk/data_dictionary/data_field_notes/p/plan/postcode_of_usual_address_de.asp?shownav=1

[100] The Office of the Chief Analyst report (2010) indicates that 'Currently national collections of A & E data do not include individual markers for no fixed abode. Therefore, there are no systematic national estimates on the use of A&E by homeless people'. Therefore, this coding may currently lack utility. Dome data is available from specialist GP practices.

[101] http://www.berkshirewest.nhs.uk/_store/documents/jsna_2011_slough_version_4a_110212.pdf

average. The episode rate per head (per person) is almost twice that in the general population. The Devon PCT JSNA (2011)[102] used the zz99 3VZ code to investigate how many patients of a specialist GP practice attended A & E. This data indicated that even those people registered with specialist health services are heavy users of acute hospital services (a range of 47-91 attendances during 2007/8 – 2009/10), perhaps due to the very complex nature of the needs of this homeless population; NHS Norfolk searched for A & E activity with a postcode of zz99 3VZ (no fixed abode) and found approximately 600 cases for the period 1st April-31st October for the years 2009-10, 2010-11, & 2011-12[103]. The need for the data was not specified.

- *Method of hospital admission (the emergency & elective split):* The Report of the Office of the Chief Analyst also reported that this population are much more likely to be admitted as emergency admissions (89%) than in the general population (41%), a ratio of emergency to elective admissions of 11.3 to 0.7; the Cambridgeshire JSNA (2010)[104] reported that 236 patients, with a no fixed abode zz99 3VZ postcode, had emergency admissions to hospital over a 5-year period (2004/4-2008/9). 30% of these were registered with a specialist GP practice for the homeless. The 171 patients who were not registered with the specialist GP practice accounted for a total of 250 emergency admissions.

- *Length of hospital stay:* The Report of the Office of the Chief Analyst also reported almost triple the length of hospital stay amongst the homeless compared with the fixed abode population aged 16-64 (6.5 vs. 2.1 days, due to the severity of their health conditions ('case mix').

- *Diagnoses for hospital admissions amongst the homeless:* The Office of the Chief Analyst's report shows that, using HRGs and episodes, the most common reasons for hospital admission for the 'no fixed abode' group are toxicity, alcohol or drugs, and mental health problems[105]; University Hospitals NHS Trust reported 422 admissions over the 5 years (2004/5-2008/9) of patients with a ZZ99 3VZ postcode for a diagnosis of drug or alcohol misuse. 15.6% were in the <25 years population. The 'no fixed abode' coding on HES has been extensively exploited in a number of research reports on homelessness by Grant Shapps (while Shadow Housing Minister), including to identify cases of alcohol misuse.

- *Emergency hospital readmissions for homeless people*: In an evaluation of a specific intervention, the Centre for Health Service Economics and Organisation (CHSEO)

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[102] http://www.devonhealthandwellbeing.org.uk/wp-content/uploads/2011/07/Homelessness-Health-Needs-Assessment-2011.pdf

[103] http://www.norfolk.nhs.uk/attendances-ae-facilities; http://www.norfolk.nhs.uk/sites/default/files/Accident-and-emergency-attendances.pdf

[104] http://www.cambridgeshirejsna.org.uk/webfm_send/110

[105] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114369.pdf

reported data for the number of episodes resulting in emergency readmissions in less than 28 days amongst the no fixed abode population, noting a fall by one third between 2009/10 and 2010/11.

- *Ratio of outpatient appointments to inpatient episodes* was roughly 1 in 4 for the NFA group compared with 1 in 6 for the general population group[106].

An additional issue is *the adequacy of the 'no fixed abode' coding* as the sole measure of homelessness. A policy issue at present is the number of people discharged from hospital back on to the streets. Coding is needed in the 'Source of Admission' and 'Destination on discharge' fields that more specifically identifies the 'usual place of residence' to which people return, including coding for hostels for the homeless, night shelters, and rough sleeping/no accommodation.

The Government commissioned a report from Homeless Link & St Mungo's[107] on how hospital admission & discharge can be improved for homeless people that showed that many homeless people are being discharged from hospital back to the street because of lack of integration between health and housing, often leading to hospital readmission. Clearly, this practice can only effectively be monitored if coding is improved on the 'destination on discharge' field. If this were the case, then it would add substantial value to NHS Outcomes Framework Indicators on Patient Experience, such as indicators in the Public Health Outcomes Framework like 'Emergency readmission within 30 days from hospital' and unplanned A & E use within 7 days. The report recommends: 'The NHS Commissioning Board(now NHS England) should introduce new standards to improve the recording of homeless patients, revising the NFA code to more accurate indicators of someone's housing status'. Without this, the report's recommendation that 'hospitals and local authorities should undertake routine monitoring and reporting of the discharge outcomes for homeless people' will not be possible. The report also indicates that more needs to be done to flag hospital readmissions amongst homeless people. This can only be done currently by analysing the patient's postcode field. Monitoring the 'self-discharged' code in the 'Method of Discharge' field in the Impatient Dataset may also be important as evidence cited in the report indicates that some homeless persons with drug/alcohol problems and poor mental health resort to this route.

Another drawback of HES inpatient data is that ethnicity is missing for around 20% of the 'no fixed abode' population, significantly higher than that for the general population, thus severely restricting the utility of ethnicity analyses.

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[106]

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114 369.pdf

[107] Homeless Link & St Mungo's. *Improving Hospital Admission and Discharge for People who are Homeless.* March 2012.

7.2.2 Use of alcohol and drug treatment services

The ***National Alcohol Treatment Monitoring System (NATMS)*** *and* ***National Drug Treatment Monitoring System (NDTMS) Datasets*** *for 2012* have an 'Accommodation need' field which has been defined with high-level reference data. The subcategories are:

- *NFA – urgent housing problem*
    - Live on streets
    - Use night hostels (night-by-night basis)
    - Sleep on different friend's floor each night
- *Housing problem*
    - Staying with friends/family as a short-term guest
    - Night winter shelter
    - Direct Access short stay hostel
    - Short term B&B or other hotel
    - Squatting
- *No housing problem*
    - Local Authority (LA)/Registered Social Landlord (RSL) rented
    - Private rented
    - Approved premises
    - Supported housing/hostel
    - Traveller
    - Own property
    - Settled with friends/family

In addition, the instruction for the 'Postcode' field states: 'If a client states that they are of No Fixed Abode (denoted by having an Accommodation Need of NFA) the postcode should be left blank.

There is a more detailed classification of 'accommodation need' for young people.

These datasets appear to be potentially very useful sources on the health of homeless people as the 'accommodation need' categories enable good capture of the Inclusion Health Board's 'vulnerable' homeless population (that is, 'urgent housing problem: live on the streets, use night hostels, and sleep on friend's floor', i.e. no fixed abode). Both are rich datasets, with in excess of 30 data items.

Data for the NATMS[108] for 2010-11 show that of 67,108 treatment journeys (i.e. clients on newly presenting for treatment) with housing situation coded, 4.0% were for 'urgent housing problem' and 10% for 'housing problem'. Of all new

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[108] Department of Health & National Treatment Agency for Substance Misuse. Statistics from the National Alcohol Treatment Monitoring System (NATMS), 1st April 2010-31st March 2011. Manchester: NDEC, 2012 (15th March).

treatment journeys (n=73,705), coding of housing situation was inconsistent/missing for 6,597 (9.0%). 82% of those reporting with 'urgent housing problem' were men, consistent with other data. Men were also more likely to present with a 'housing problem'. Clients aged under 30 were twice as likely to have a housing problem as older clients.

Similar *Data for the NDTMS[109]* for 2010-11 show that of 71,322 treatment journeys (i.e. clients on newly presenting for treatment) with housing situation coded, 9.0% were for 'urgent housing problem' and 15% for 'housing problem'. Of all new treatment journeys (n=74,028), coding of housing situation was not stated/missing for 2,706 (3.8%). Opiate users were much more likely to have no fixed abode and a housing problem than other clients.

7.2.3 The use of mental health services

Data on the use of mental health services by homeless people is a major gap.

Mental Health Minimum Data Set (MHMDS): Though data is collected on the postcode ZZ99 3VZ, patients of no fixed abode are not identified in commissioner extracts. The MHMDS extracts provided to commissioners and other users of pseudonomised data only include the first part of the postcode and so default postcodes indicating no fixed abode (ZZ99 3VZ) have never flowed in MHMDS (i.e., only ZZ99 flowed). If such information is required by commissioners, the NHS Information Centre indicates that this will need to be addressed in a future version of MHMDS by means of an additional data item[110].

National Mental Health & Learning Disability Ethnicity Centre in England and Wales, 2010: This situation is not remedied by the Count-Me-In Censuses. The Data Capture Protocol states: 'It would help if the following pseudo postcodes could be used where the patient's postcode is unknown: ZZ99 3VZ = No fixed abode; ZZ99 3WZ = Not known. However, the protocol adds: 'The completion of postcode in previous Censuses has been low and many patients were given the same postcode as the provider'[111].

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[109] Department of Health & National Treatment Agency for Substance Misuse. Statistics from the National Drug Treatment Monitoring System (NDTMS), 1st April 2010-31st March 2011. Manchester: NDEC, 2011 (6th October).

[110] http://www.ic.nhs.uk/services/mental-health/news-and-developments/mental-health-information-update-first-full-mhmds-v4-quarterly-release--q1-final-data-and-q2-provisional

[111] https://www.countmeinonline.co.uk/docs/Protocol%20Document%202010.pdf

7.2.4 Health and Social Care Information Centre (HSCIC) Datasets that record 'no fixed abode' postcode or 'homeless'

There are a range of other HPA and HSCIC National Datasets where the dataset specification includes the 'no fixed abode' postcodes. Some of these datasets are new or still to be finalised. They include:

- *Community Information Dataset[112]:* The Community Information Dataset is intended for secondary uses purposes using data collected by community service providers as a result of direct care of the patient. Information in the dataset will be extracted from community provider IT systems from the data recorded as part of the care process. The data items include 'postcode of usual address'. If a patient has no fixed abode, the guidance states that this should be recorded with the appropriate code (ZZ99 3VZ).

- *Children's and Young People's Health Services (CYPHS) Secondary Uses Data Set:* the specification states: Post code (main permanent residence): If the person has no fixed abode the NHS service will submit ZZ99 3VZ.

- In the *Maternity Services Secondary Uses Dataset* the mother's demographics include an 'Accommodation Type (mother at booking)' field, the coding for which includes: 'Temporary Accommodation (to continue/to cease after pregnancy)', 'Homeless'. It has not been possible to assess the utility of this coding in reported statistics from the dataset.

- *Chlamydia Testing Activity Dataset*: Under postcode of usual residence, the specification indicates that: 'If a patient has no fixed abode, this should be recorded with the appropriate code (ZZ99 3VZ)'[113].

- *Cancer datasets:* Some of the cancer datasets in the NHS Information Centre's National Datasets Service include the same statement regarding no fixed abode.

- *Improving Access to Psychological Therapies Dataset[114]*: Under 'postcode of usual address', the dataset specification indicates: use of default postcode ZZ99 3VZ for no fixed abode.

- *NHS Health Check Dataset*: Under postcode of usual address, the specification states that 'If the cohort has no fixed abode, then the code ZZ99 3VZ should be used.

- *Rio Standards for primary & community care*: The patient's current address field indicates: No fixed abode – ZZ99 3VZ.

- *Trauma Audit & Research Core Dataset[115]:* This was launched January 2011. Under 'patient postcode' the dataset specification indicates: 'No fixed abode: ZZ99 3VZ'.

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[112] NHS Information Centre. *Community Information Data Set. User Guidance. Version 1.0.* 2011 (February).
[113] http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1309969751013
[114] http://www.ic.nhs.uk/webfiles/Services/Mental%20health/IAPT_validation_summary_v1.1.pdf
[115] www.tarn.ac.uk/content/downloads/53/Core_ppguide.pptx

7.2.5 Health Surveys

- There is currently only limited coverage of the homeless population in health surveys and this is an area where data capture could be improved, including consideration of commissioning specialist health surveys for this population (such as the Multiple Exclusion Homelessness Survey, 2008/9-2011-12). A search of the Survey Question Bank identified no surveys that capture rough sleepers in their coding. However, some do code 'a hostel for the homeless', including some of the cohort studies.

7.2.6 Health-related datasets for homeless people in prison

In 2011 a national clinical IT system for prison healthcare was released which has been adopted by all 136 prisons in England as an important element in reducing health inequalities and improve healthcare for, and the rehabilitation of, offenders[116]. It allows GPs working in prisons to share records between prisons electronically, instead of having to wait for paper records to arrive and provides immediate, 24-hour access to this information. Moreover, when a prisoner is released, GP practices in the community should now receive better quality health information from prisons. However, related datasets have not yet been published by Connecting for Health so it is unclear whether the homeless (and other vulnerable groups) are flagged. P(Prison)-Nomis (Prison National Offender Management Information System) collects very limited data on offender characteristics (sex, ethnicity, age group, religion, nationality, and criminal history as a maximum but much more limited in most published tables) but, as noted, the ethnicity field does include Gypsies and Travellers. Ministry of Justice youth offender assessment forms do not provide indicators of homelessness or sex work. However, 2011 Census tables on communal establishments have a category on 'prison service establishments'. There is, too, a 'checklist for discharge of prison clinical substance misuse patients to community substance misuse services' that may identify homeless persons through the release address and contact details[117].

7.3 Specific sources on homeless people

There are a range of specific sources on the homeless population, some of which provide counts on segments of the homeless population, such as rough sleepers and the statutory

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[116] http://gp.dh.gov.uk/2011/05/27/national-clinical-it-system-for-prison-healthcare/

[117] http://www.nta.nhs.uk/uploads/idts_discharge_checklist_final.pdf

homeless, and others providing a point of access to health-related data via the specification of 'primary client groups'.

7.3.1 'Supporting People' (SP) data

'Supporting People' is a UK government-funded programme which commissions housing-related support services, including homeless hostels, supported accommodation for various client groups, women's refuges, sheltered housing for the elderly, and floating support for people in their own home. SP services are non-statutory and are generally open to anyone aged 16 years and over with a housing related support need. The funding comes from Communities & Local Government (and therefore separate from health and social care). Since its launch in 2003, the level of funding has reduced in recent years and in 2009 the ring fence was removed from the grant thereby allowing local authorities to spend their allocation as they deemed fit[118].

In April 2011, the DCLG ceased collection of Supporting People Client Record and Outcome data, when the Supporting People programme funding rolled into Formula Grant (the blanket term given to the main sources of general Government funding for English local authorities). Hitherto, SP providers had been required to complete and submit a client record form for each person entering their services. The form records information on primary and secondary client group, age, ethnicity, gender, economic status, referral source, and prior accommodation. Clients are categorised according to 'primary client group'. This is a drawback as the categories are not mutually exclusive, for example, a person may fall into 'rough sleepers', 'single homeless', 'offenders', 'people with drug problems', and 'people with mental health problems'. Which category the person is allocated to may depend on which service saw the person. Thus, the data cannot be used to identify homeless people treated by these specialist services with a dual diagnosis of coexisting mental health and drug and alcohol problems. A further disadvantage is that the information is collected each time a person accesses a service so the reported data are on contacts with services and not individual people (the forms are anonymised so the contacts count cannot be converted into a person count). However, the data can be used to provide, by reporting year: number of presentations to services by gender; number of presentations to services by primary client group (single homeless, rough sleepers, homeless families, domestic violence (women), young people at risk, mental health problems, alcohol problems, drug problems, offenders/ex-offenders, teenage parents, young people leaving care); the age and ethnicity profile of SP client records by primary client group; and sources of referral by primary client group. The SP data also provides information on whether the client was considered to be statutorily homeless and in priority need.

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[118] House of Commons Library. *The Supporting People Programme. Research Paper 12/40*. London: House of Commons Library, 16 July 2012. Accessed at*: www.parliament.uk/briefing-papers/RP12-40.pdf

There is a central reporting system to the Department of Communities & Local Government[119]. However, it is important to note that the coalition administration has decided that it will no longer require local authorities and providers of services to submit ongoing data returns to government on Supporting People services[120]. *Supporting People Client Records* data provides information about characteristics of clients entering Supporting People services. This data is collected each time a client enters a housing related support service funded by Supporting People. *Outcomes for short-term services* data provide information about characteristics and outcomes achieved by clients leaving short-term Supporting People services. This data is collected each time a client exits a short-term (more than 28 days but less than two years) housing related support service funded by Supporting People.

Outcomes for long-term services data provides information about characteristics and outcomes achieved by clients in receipt of long-term Supporting People services. This data is collected for a sample of clients in long-term (over 2 years) services after completion of their annual support plan. The sample is 10 per cent for older people services and 50 per cent for all other service types.

The Supporting People Client Records and Outcomes data tables provide a breakdown of:

- Client Records data by service type and primary client group;
- Outcomes for short-term services data by service type, primary client group and outcomes achieved against identified support needs; and
- Outcomes for long-term services data by outcomes achieved against identified support needs.

Key headline figures from the 2010-11 data tables are: 231,200 Client Record forms were received. The most frequently occurring primary client group (i.e. predominant need of the client as defined by the service provider) is single homeless with support needs (26 per cent), followed by people at risk of domestic violence (11 per cent).188,900 outcomes for short-term services forms were received. 39,900 outcomes for long-term services forms were received. From the viewpoint of JSNA work, these data are available at a local authority level. However, the central reporting system has been discontinued so only historic data are now available.

7.3.2 Official rough sleeper counts/estimates

Procedures for counting/estimating the rough sleeper population have been revised by the coalition administration. Now all local authorities have to provide a count or estimate of rough sleepers, replacing a system where only local authorities with a known or suspected

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[119] http://www.communities.gov.uk/publications/corporate/statistics/supportingpeoplefinal2011

[120] HM Government. *Vision to end rough sleeping: No Second Night Out nationwide*. London: Department for Communities and Local Government, 2011 (July).

rough sleeping problem were required to provide a count. Also, the counting/estimating procedures have been made more robust.

Under these procedures, it is up to local authorities whether they undertake an official rough sleeper count with regard to the rough sleeping problem in their area. If an authority chooses not to conduct a count, it still has to provide an estimate of the number of rough sleepers on a typical night. Rough sleeping counts and estimates have to be undertaken between 1st October and 30th November. Communities and Local Government provides guidance on evaluating the extent of rough sleeping via counts or estimates and Homeless Link provides a detailed toolkit to support local authorities and their partners to accurately evaluate the extent of rough sleeping. The 'Rough Sleepers' local authority form[121] contains sections on the *count of people sleeping rough* (recording total count of rough sleepers and date of the count) and *estimate of people sleeping rough*, that is, the number of people thought to be sleeping rough in the local authority area. In making the estimate local authorities are advised to bring together local agencies with the most accurate information on rough sleeping. The form records the estimate of number of rough sleepers and a list of agencies to be ticked who assisted in making the estimate (voluntary sector, faith groups, outreach workers, local residents/businesses, police, mental health agencies, substance misuse agencies, and drug and alcohol treatment teams). Local authorities submit the form to Communities & Local Government. Local authority level historical data is available going back to 1998.

These counts of the rough sleeper population are 'snapshots', not designed to pick up all rough sleepers over a period of time. Moreover, this source provides no information on the health and social care needs of the rough sleeping population. The annual increases in the percentage of people seen sleeping rough by outreach teams has been greater than that recorded for these snapshot street counts, possibly pointing to people having shorter spells of sleeping rough.

7.3.3 Statutory homeless returns[122]

Key information about local authorities' discharge of their duties under homelessness legislation is collected on quarterly P1E returns. All returns undergo thorough validation to ensure that data are as complete and accurate as possible and typically at least 98 per cent of authorities provide data. Estimates are made for missing returns, along with imputations for any incomplete data, and summary results are published in a quarterly Statistical Release by the Department for Communities and Local Government, in accordance with National Statistics Code of Practice. DCLG publishes quarterly statistics (listing decisions, broken down by acceptances, intentionally homeless, homeless non-priority, & not homeless); data are also reported on households in temporary accommodation. While the statutory homeless

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[121] http://www.communities.gov.uk/publications/housing/roughsleepingevaluate
[122] Data for another group in the vulnerable housing population with less high health needs is the hidden homeless. Hidden homelessness is measureable using national datasets (including the English Housing Survey and the LFS).

fall within the Department of Health's definition of 'vulnerable' homeless, their health needs tend to be less high than the rough sleeping population, people sleeping in a hostel, and people in insecure or short-term accommodation, such as in a squat or on a friend's floor.

7.3.4 Local authority data on the homeless

Local authorities use a wide range of outreach and service models that reflect their own circumstances. Some local authorities have established their own databases on the homeless, drawing on data from the main providers of accommodation and support services (such as Cyrenians, Centre 33, church-based projects, outreach projects, YMCA, etc.). Such databases mainly capture the single homeless and rough sleepers, a population that is often different from the statutory homeless. However, information is generally collected on contacts rather than people and not all service providers in a particular local authority may contribute to such databases. Moreover, some single homeless and rough sleepers may have very little or no contact with accommodation/service providers. The content of such databases varies: the Cambridge City Council database, for example, includes reason for homelessness, what services the client is engaged with, and what additional services the client requires, and an assessment of whether the client's needs are being met. Local authorities may also draw on estimates of the single homeless (in hostels, shelters & temporary supported accommodation) based on Citizen's Advice caseloads.

7.3.5 Specialist London databases and dedicated GP practice/surgery computerised records

The London rough sleeper database allows the flow of new rough sleepers to be monitored. The Chain database (Combined Homelessness and Information Network (CHAIN) database)[123], managed by the homeless charity, Broadway, records information about contacts with rough sleepers made by outreach teams and other actions such as accessing short-term accommodation. The database also records support needs with respect to drug and alcohol misuse and mental and physical health needs. It is the most comprehensive source of rough sleep information in England and contains records, beginning in the late 1990s, about more than 13,000 individuals rough sleeping in London. In London there is also a Clearing House (CH) Dataset about former rough sleepers who have moved into long-term accommodation that had been ring-fenced for rough sleepers initially as part of the Rough Sleepers Initiative. Data is now frequently recorded and computerised in GP specialist practices for the homeless, such as those in Leicester[124] and Cambridge.

7.3.6 Use of postcode of hostels & default postcode of dedicated GP practices: Where the no fixed abode postcode is exploited in JSNAs (as in the Cambridgeshire 2010 JSNA), some

[123] NatCen. Profiling London's rough sleepers: http://www.natcen.ac.uk/study/profiling-london's-rough-sleepers
[124] Hewett N, Hiley A, Gray J. Morbidity trends in the population of a specialised homeless primary care service. *British Journal of General Practice* 2011; 61(584): 200-202.

investigators have attempted to maximise capture of the homeless population in data by also including: (i) the postcode of dedicated general practices/surgeries that provide specialist homelessness services, where homeless persons give this as their default postcode; and (ii) postcodes of hostels and night shelters for the homelessness. Clearly, this strategy is likely to maximise capture of the vulnerable homeless.

7.3.7 Operational client data:

There is considerable data about health collected by providers of housing related support which is currently being underused. While such data is not a standardised data set, it may nevertheless yield useful data.

7.4 Major Gaps

Sources on homeless people with mental health problems. Sources are few, the MHMDS and Count-Me-In Censuses lacking coding on homelessness or 'no fixed abode'. The HES admitted patient care (day case and ordinary admissions) dataset provides the best data source. Studies show that data on the health of the homeless can be captured through the HES *HRG system*, particularly the HRG Chapter on 'mental health' and HRGs within the Chapter (alcohol or drugs dependency, alcohol or drugs non-dependent use, schizophreniform diagnoses, acute reactions or personality disorders), and also through *Specialty* coding which includes Adult Mental Illness and the *Diagnoses* fields which provide additional detail.

Sources on homeless people with dual drugs / alcohol and mental health needs. The only source that might throw light on this is the HES admitted patient care dataset and, in the case of rough sleepers, the CHAIN database. The method used for recording Supporting People data is structured by primary client group with no means of record linkage. This group is significant amongst rough sleepers: amongst first-time rough sleepers in London in 2007, around a fifth were found to have a mental health problem combined with a drug or alcohol support need.

Alcohol & drug misuse: The utility of the two treatment monitoring system datasets has been overlooked with respect to the health of the homeless/no fixed abode population. Both are rich datasets with respect to the number of data items and have coding that can differentiate a spectrum of vulnerability and address dual diagnoses.

Other conditions: Some specialist GP databases show that a high percentage of cases presenting have a diagnosis of 'fracture' and 'assault' and that the proportions have been increasing over the last 10 years. There may be a further point of access to these trends via HES data.

8. USE OF ROUTINE AND OTHER DATA SOURCES FOR SEX WORKERS

8.1 Definitional issues and comprehensive denominator data

The literature shows that there are complex issues regarding both definition and capture, including conflation of sex workers with trafficking and abuse. The terminology is also contested, with 'sex workers' now being the preferred term (rather than 'prostitutes' which is considered to stigmatise sex workers). The term is generally regarded as encompassing street and indoor venues (including brothels, flats paid for by pimps, and sex workers' own accommodation), and including men, women, and transsexuals. However, as Cusick *et al.* (2009) have written, much of the recent government commentary on sex workers has served the purpose to '…reinforce a stereotype of sex workers as exclusively female and vulnerable', thereby marginalising the importance of male and trans workers (with the risk that they are excluded from services set up for women). Generally, less is known about male and trans sex workers. Cusic *et al.*'s data from 38 responding specialist services for sex workers revealed that 8.8% (of 12,215 clients) were male sex workers. However, of 4,173 street-based sex workers, only 5 were street-based men. There may be wide differences between these sex markets in terms of the vulnerability of sex workers, especially between street and indoor sex markets.

The prevalence of the sex worker group in the general population is widely disputed, there being no reliable estimates for resource allocation of targeted health and support services. Nor is there information on how sex workers are distributed across the different sectors of the industry (street workers; indoor sex workers; migrant sex workers; sex workers who are victims of trafficking, controlled by another person, or forced to sell sex; female, male, and transgender sex workers; and sex workers who are intravenous drug users). Surrey's JSNA (2011), for example, could only state: 'The prevalence of men and women involved in sex-work in Surrey is believed to be similar to that for other counties in the UK'. Westminster's JSNA (2010) indicates: 'It is difficult to provide robust estimates of the numbers (of sex workers) living/working locally'. There is evidence that London has a disproportionately high number of sex workers. A mapping of commercial sex activity in London in 2004 located 730 flats, saunas and parlours where sex workers were operating. This is likely to be an underestimate of commercial sex activity as the mapping focused on female sex workers and not all sites were identified in the mapping exercise. It was estimated between 2,972 and 5,861 women were working at these sites across London. With respect to individual London Boroughs, 39 sites were located in Croydon, one of which was fully licensed, estimates of the number of sex workers in the borough being put at between 100 and 350[125], Croydon's JSNA (2010-11) reporting around 300 sex workers working in brothels in the borough.

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[125] Dickson (2004). *Sex in the city : mapping commercial sex across London*

With regard to other cities, Nottingham estimated in its 2009 JSNA that there were an estimated 130-150 street prostitutes working in the city, with a further 100-200 off-street sex workers working in saunas, brothels, massage parlours, or from their own homes; there are also around 15 known male street sex workers. This JSNA further adds: 'Nottingham has similar numbers of street prostitutes to some other cities of its size in the UK, for example, Bristol, Sheffield, and Liverpool. However, prostitute statistics are very variable between different cities, since not all cities have sex worker support projects and hence the numbers are sometimes simply not known'. All these difficulties in counting stem from the fact that sex workers are a largely hidden population and this position is sustained by the fact that significant stigma attaches to sex work and that some sex work-related activities are criminalised. Thus, the use of 'sex worker' as a category in official datasets is problematic with respect to issues of confidentiality and risk of disclosure, resulting in few attempts to capture this group in official data collection.

A key issue is who should be counted as a 'sex worker' for the purposes of JSNAs. There are a number of perspectives. Firstly, there is the issue of *self-identification*, whereby persons are only counted as sex workers if they self-identify as such. The alternative to definition based on self-ascription – which may substantially undercount this population – is the use of an *operational definition* that would capture this population. Clearly, this involves a consideration of what counts as sex work (for example, there may be grey areas such as phone sex operators, erotic dancers, etc.) and whose definition is used. From a health services or epidemiological perspective Cusick *et al*. (2009) consider that an important component of the definition is that the motive for sex is money. These investigators also caution that trafficked, exploited and abused women and children are routinely conflated with adults in sex work by their own choice. Moreover, male and transgender sex workers are frequently ignored. The Kinnell (1999) and Cusick *et al*. (2009) studies use a definition of sex workers that encompasses those working on the streets, in massage parlours, in flats, and as part of an escort service, to the exclusion of the wider sex industry. This is as probably as close to a satisfactory definition that can be achieved. Moreover, it is with these groups that the majority of specialist services are working.

Given the poor availability of baseline/denominator data on sex workers at the local authority level (though some authorities have used client counts for specialist and other services in an attempt to derive accurate estimates), other strategies are needed for the capture of vulnerable sex worker populations.

Capture-recapture study designs:

Capture-recapture methods were first used to estimate the size of animal populations but have been adapted for use in human populations[126]. The method estimates the size of a hidden

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[126] Hook EB, Regal RR (2004). Completeness of Reporting: Capture-Recapture Methods in Public Health Surveillance. *In Monitoring the Health of Populations: Statistical Principles and Methods for Public Health Surveillance*, R Brookmeyer, DF Stroup, eds., Oxford University Press, New York, pp. 341-359.

population by identifying its members in at least two *independent* samples and working out the extent of overlap between the samples using the following formula:

$$N = \frac{(M + 1)(C + 1)}{R + 1} - 1$$

Where:

N = total number of cases in the study population

M = number of cases found in the first sample

C = number of cases found in the second sample

R = number of cases found in both samples

This approach could potentially yield reasonable estimates of the vulnerable population groups. However, multiple discrete sources of overlapping data that uniquely identify individuals are clearly needed. This is frequently problematic with respect to sex workers because of confidentiality issues (relating to stigma and criminalisation of sex workers). There are therefore likely to be significant difficulties in obtaining access to specialist service data on individual clients. There may be some limited scope (subject to obtaining consents) to utilise capture-recapture on some generic health datasets (such as those for genito-urinary medicine and sexual health clinics) though the population captured would be that with multiple health needs. Some examples of the use of this method to estimate the size of the sex worker or injecting drug user population have been found but only one is specific to the UK[127].

Multiplier methods of estimating prevalence

This method has been used by Kinnell (1999) and Cusick *et al.* (2009)[128] to estimate the size of the sex worker population in Britain. In Kinnell's 1999 study an estimate was made of sex

[127] Frischer M, Bloor M, Finlay A, Goldberg D, Green S, Haw S, McKeganey N, & Platt S. A new method of estimating prevalence of injecting dug use in an urban population: results from a Scottish city. *International Journal of Epidemiology* 1991; 20: 997-1000; Kruse N, Behets F, Vaovola G, Burkhardt G, Barivelo T, Amida X, & Dallabetta G. Participatory Mapping of sex trade and enumeration of sex workers using capture-recapture methodology in Diego-Suarez, Madagascar. *Sexually Transmitted Diseases* 2003; 30(8): 664-70; Mastro TD, Kitayaporn D, Weniger BG, Vanichseni S, Laosunthorn V, Uneklabh T, Uneklabh C, Choopanya K, & Limpakarnjanarat K. Estimating the number of HIV-infected injection drug users in Bangkok: A capture-recapture method. *American Journal of Public Health* 1994; 84(7): 1094-9.

[128] Cusick L., Kinnell H., Brooks-Gordon B., Campbell R. Wild guesses and conflated meanings? Estimating the size of the sex worker population in Britain. *Critical Social Policy* 2009; 29(4): 703-719.

workers (those based on streets and indoors; women, men, transsexuals) based on information supplied by services. 16 services estimated the number of sex workers thought to be operating in their geographical areas, based on the number of sex workers who used their services, local knowledge and known research. The average number of sex workers per reporting service was 665: this figure was then multiplied by 120 which was the number of services in the UK known by Kinnell to be working with sex workers. These 120 services included both specialist projects for sex workers and non-specialist agencies such as Genito-Urinary Medicine (GUM) and drug services. This gave an overall estimate of 79,800 sex workers. This method, then, would yield an estimate of the number of sex workers who are in contact with – or on the case files of – specialist and other services, often recorded in monitoring data (but not necessarily all those in need) and estimates of all sex workers operating in a particular area.

Since the late 90s there have been a number of changes. There is some evidence, for example, that the number of sex workers working against their will and under the control of pimps and traffickers (including some of those who have come from abroad) has increased. In the Cusick *et al.* (2009) study, 54 specialist agencies in England and Scotland on the UKNSWP 2007 directory listing were invited to participate. All the specialist services were asked to report the number of sex workers with whom they were in contact and the sector they worked in during 2007/8. 38 of the specialist services consented. For non-responding services figures were estimated as averages of the responder data. To estimate the number of sex workers not in contact with specialist services, the mean average number of sex workers in contact with specialist services was compared with the mean average number of sex workers *thought to exist* in the area of the specialist services in the Kinnell (1999) study. These figures suggest a multiplier of 1 : 2.1 to move from sex workers in contact with services to a wider estimate of sex workers in Scotland and England.

The two approaches may be summarised, thus:

Deriving base figures from services:

1. What type of service?

- Kinnell (1999): Data from various types of service known to provide services for sex workers;
- Cusick (2009): Data only from specialist services.

2. What were services to report?

- Kinnell (1999): Asked services to estimate the number of sex workers operating in their geographical area.
- Cusick (2009): Recorded the number of self-reporting sex workers using specialist services in a 1-year period.

3. Use of multipliers

- Kinnell (1990): Multiplied the average estimated number of sex workers per reporting service by the number of services working with sex workers. Mean 665 x 120 = 79,800.
- Cusick (2009): The figure of 665 (projects' estimate of the number of sex workers they thought existed in their area) was 2.1 times the 316 sex workers Cusick (2009) found using specialist services. Using this multiplier she proceeds from the number of sex workers using specialist services (17,087) to an estimate of the sex worker population of 35,882 that takes account of local knowledge (that is, mean 316 x 2.1 x 54 = 35,882).

If this method is applied to JSNAs at the local authority level, then the method would require investigators to establish the number of clients using specialist sex worker services in the area and use the multiple of 2.1 times to obtain an estimate of all sex workers. There are, however, some drawbacks to the method which render the estimates indicative at best. Kinnell's estimates were based on only a small number of services and may have involved some double counting of those using more than one type of service. Equally, the Cusick (2009)'s focus on specialist services risks excluding some categories of sex worker (notably, indoor workers) who are less targeted/less known to services. Moreover, some sex workers may not use these services, relying on generic GUM or drug treatment services. However, this approach minimizes double counting.

Relying only on the count of sex workers in contact with specialist services would clearly exclude those unaware of such services or who choose not to access them. Moreover, there may be many areas where no specialist services are commissioned for sex workers. Thus, this method can only be used where there are specialist services. Moreover, the few services commissioned to meet the needs of male sex workers may significantly undercount this population. Cusick (2009) also notes that sex workers in escort agencies tend to be less targeted by specialist services than street workers and those working in massage parlours and flats.

8.2 *The capture of the sex workers population in routine health and social care datasets*

8.2.1 *Sexually transmitted infections:*

Some use of 'sex worker' categorisation is found on sexual health databases. Sex workers are a specific target group identified by the Department of Health for sexual health promotion and interventions. *Genitourinary Medicine Clinic Activity Data Set* (which replaced the retired KC60 Central Return in 2009) has a 'Special Patient Groups' field which provides additional information on certain patient groups receiving services or undergoing tests. The 'Sex Worker' (SW) code is used in the case of provision of a service to a patient known to be a current sex worker, to be reported at each first

attendance. These data are unavailable as aggregates prior to 2011 and are sourced from the GUMCAD SHHAPT[129] codes. These data were first reported for the 2011 data year and are significantly underreported due to the phased introduction of SHHAPT codes during 2011 (Jan.-Dec.). They show number of selected STI diagnoses in the 'sex worker' population across England, that is: chlamydia, 250 diagnoses; gonorrhoea, 96; herpes, 45; syphilis, 9; and warts, 60 diagnoses. Besides London, counts at Strategic Health Authority level were a dozen or fewer for each of the five diagnoses.

8.2.2 Drug treatment services:

The 'Sex Worker' category data item has been removed from the *National Drug Treatment Monitoring System's Core Data Set*[130]. This item was previously included within the data set for collection and use at regional level only. Following consultation, it was decided to remove this data item at the April 2011 revision. The NDTMS systems have been amended to exclude any data submitted in this field and to cease any entries from being uploaded onto the database. This decision is unfortunate as completeness of the item was high in some local authorities. For example, the NE Public Health Observatory reported completeness for this item (over the current year) in October 2009 for the 12 NE Region local authorities: the rates were 83.8% of 2059 episodes active in the year; 83.4% of 4590; 99.8% of 2586; 94.9% of 3960; 90.7% of 10,080; 91.2% of 3,690; 76.0% of 7,457; 71.0% of 2276; 69.7% of 4186; 84.6% of 4373; 69.6% of 3522; and 83.2% of 9153).

However, some drug misuse assessment forms used by administrative authorities (local and county councils) use 'sex worker' categorisation, e.g. Kent County Council's 'Adult Substance Misuse Combined Assessment Form' (used for triage assessment)[131], has a source of referral field ('sex worker project') and 'sex worker status' field (categories of 'sex worker', 'selling sex on the street', 'involved to fund their habit', and 'selling sex from premises').

8.2.3 HIV and AIDS Reporting:

In the *HARS Dataset* (the HIV and AIDS Reporting System replaced SOPHID & new HIV diagnoses) (3rd April 2012), there is coding for sex worker (Is the patient CURRENTLY a sex worker? Y=Yes; N=No).

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[129] Known as Sexual Health and HIV Activity Property Type Codes which became effective on 1st January 2011. See: Health Protection Agency & British Association for Sexual Health & HIV. *Revisions to KC60 (SHHAPT) codes: Specification and rationale*. 1st July 2010.
[130] The NDTMS is administered by the NHS National Treatment Agency for Substance Misuse.
[131] See: https://shareweb.kent.gov.uk/Documents/KDAAT/2012-02_v4combined%20form.pdf

8.2.4   Health Protection Agency microbiology report forms:

The <u>STI and BBV</u>[132] <u>Investigation (Health Protection Agency) through Microbiology request form</u> has a 'Risk group' data item (IV Drug User, Commercial sex worker, Heterosexual; Homosexual/Bisexual; No known risk). These data are managed by the HPA's Virus Reference Department at Colindale. Tests undertaken on dried blood spots/oral fluid comprise antibody screens for HIV, Hepatitis C, Hepatitis B, and Syphilis. If the blood test confirms infectious syphilis, a health adviser and the patient complete a confidential and anonymous questionnaire for the *Enhanced Infectious Syphilis Surveillance Programmes* in England and Wales that asks if there was contact with a commercial sex worker.

8.2.5   Mental health services

There is no coding for 'sex worker' in *the Count Me In 2010 National Census of Inpatients and Patients on Supervised Community Treatment in Mental Health and Learning Disability Services in England and Wales*, nor on the *Mental Health Minimum Dataset*.

8.2.6   Hospital services

There is **no coding for 'sex worker' (or 'prostitute')** on the HES Admitted Patient Care Dataset, HES Outpatient Dataset, A & E HES Dataset, HES PROMS Dataset, Adult Critical Care Dataset, and the ONS-HES Linked Mortality Dataset.

8.2.7   Primary Care Services:

There is only limited **generic use of 'sex worker' categorisation** in health care settings. The category 'Sex worker' (0AL) was added to the **NHS Read Codes** in Q1 2011 & 'Former sex worker' (14Of) was added Q1 2012[133]. Although now available, these codes are unlikely to be extensively known by general practice staff and it is likely that cases will be significantly underreported.

8.3   Other sources on Sex Worker Health to Populate Gaps:

8.3.1 Records of service agencies for sex workers

In London and other towns and cities with a significant concentration of sex workers, the most comprehensive data source on sex workers is likely to be *the records of service agencies for sex workers*. These may encompass specialist services for sex workers (those that provide a dedicated service for sex workers or with dedicated staff working with sex workers), outreach and/or drop-in services for a range of health and

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[132] STI (sexually transmitted infections) and BBV (blood borne viruses)
[133] NHS Connecting for Health. *Change Report for the April 2012 Medical Read Codes Release.*

welfare services (including sexual health, drug treatment, primary health care services, education, housing, and protection from violence), and non-specialist services, such as Genito-Urinary Medicine and drug services where sex workers are part of a wider clientele. Such agencies may be health- or local-authority led, sex worker led, voluntary organisations, or charitable bodies.

The UK Network of Sex Work Projects (UKNSWP) is the most comprehensive source of data on projects for Sex Workers. This is an umbrella organisation representing and sharing information on good practice between projects that offer specialist support services to people involved in sex work. Its online directory of 202 sex work projects, searchable by Government Office Region (http://www.uknswp.org/projects/), is the most comprehensive source of such projects and also offers a sampling frame. JSNA's may find the list useful as an initial point of access to sex work projects and specialist services in local authority areas.

Most large cities have such services (e.g. 'Prostitute Outreach Workers' [POW] and 'Jericho Project' in Nottingham; Open Doors in Hackney; the Praed Street Project and Working Men's Project in Westminster set up by Imperial College Healthcare Trust; CLASH [Central London Action on Sexual Health] outreach in Soho, King's Cross and Islington flats; and SW5 (Streetwise), Terrence Higgins Trust; and SWISH [Sex Workers into Sexual Health], Terrence Higgins Trust). JSNAs and other sources provide some examples of statements on the number of contacts cited by these projects. In 2007 POW indicated that they made 1,997 'prostitute' contacts, including 59 new contacts; Jericho Road Project were not able to estimate the number of women seen in a year (Nottingham JSNA, update April 2009). Between 2006-2008 Hackney's Open Doors made contact with nearly 200 women per year, rising to 260 in 2009; the Praed Street Project and Working Men's Project in Westminster recorded 3,040 and 1,178 contacts, respectively, over the course of a year[134]. Surrey estimated 100-150 sex workers in the county in any given week, based on the use of its services (74 Team contacts per month) and additional estimation (Surrey JSNA 2011), and an additional 13 young people at risk of sexual exploitation (regarded as an underestimate).

8.3.2 Local authority (or joint partnership) drug and alcohol treatment services:

While centrally reported use of NHS drug treatment services now omits 'sex worker' coding, _local authority (or joint partnership) drug and alcohol treatment services_ are more likely to include coding for 'sex worker' in their referral forms. For example, the London Borough of Harrow's 'Compass Harrow' uses a referral form that includes coding for 'sex worker' ('selling sex on the street', 'selling sex from a

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[134] See:
http://westminstercitypartnership.org.uk/Partnerships/Health%20and%20Wellbeing/JSNA%20%20Completed%20Needs%20Assessments/JSNA%20-%20Sexual%20Health.pdf. The Working Men's Project contacts comprised: 433 outreach contacts (117 internet and 316 brothel) and 745 clinic episodes.

premises', 'not a sex worker'). Kent County's 'Adult Substance Misuse Combined Assessment Form' includes fields for: 'referral' ('sex work project') and 'sex worker status' ('sex worker'; 'selling sex on the street', 'involved to fund their habit', and 'selling sex from premises'). The joint Waltham Forest Council/NHS Waltham Forest referral form to Waltham Forest Substance Misuse Partnership includes coding for 'sex worker'. North Essex Partnership Substance Misuse Services uses a Comprehensive Assessment Form that includes the questions 'Is the client a sex worker', 'If yes, selling sex on the street', and 'selling sex from premises'. Buckinghamshire Drug and Alcohol Referral Form also uses this coding.

Where more than one agency or statutory body collects data on sex workers, for example, substance misuse and sexual health services, there may be scope to develop data-sharing protocols if they do not already exist.

8.3.3 Police estimates

Bristol's JSNA (2012) reported that in September 2011 the police estimated 280 women working in the sex market in Bristol and an estimated 126 women working in 25 parlours in Bristol. Police estimates in Nottingham are in broad accord with other estimates. During 2004-5 222 different women involved in street prostitution were dealt with by Nottinghamshire police (Nottingham JSNA, 2009): this compares with 130-150 female street prostitutes working in the city area, & a further 100-200 off street sex workers.

8.4 Main gaps

There are a number of key gaps. Currently, 'sex worker' is poorly recorded in datasets for sexual health/sexually transmitted infections (largely because these datasets are new). There is now no 'sex worker' coding on the key national dataset for drug misuse. There is no 'sex worker' coding on the national dataset for mental health, nor on the former series of Count-Me-In censuses.

9. Approaches to future measurement

There may be other areas which have not been the focus of routine data collection nor hitherto of JSNAs where local data collection could provide a wider knowledge base to inform health improvement strategies. The latest - July 2012 - guidance on 'enhanced' (post-Health & Social Care Act 2012) JSNAs require health and wellbeing boards to consider what local communities can offer in terms of assets and resources to help meet the identified needs, to be incorporated into the narrative on JSNA evidence. The relevant provisions of the 2012 Act will come into effect in 1st April 2013. The Department of Health has identified a range of assets within local communities that can help meet identified needs and impact on the wider determinants of health, including formal and informal resources and capacity in the community and various organisations, that might enable groups to take greater control of their own health.

Community asset mapping

There has been an interest amongst bodies such as the Transition Alliance[135] and the Improvement and Development Agency's (IdeA) Healthy Communities Programme[136] in asset mapping (a process which identifies the capacity, skills, knowledge, connections potential, and social capital in a community), asset based community development approaches, and asset driven approaches to the whole commissioning cycle. The North West Asset Group has taken a lead and recently produced a report: 'Development of a Method for Asset Based Working' (March 2011)[137]. Asset approaches are seen as a way of helping communities to gain confidence, identify their own priorities, and contribute to community-led ways of effecting health improvements. The approach involves bringing people together to identify individual skills and audited community fabric (such as allotments). One application in the North-West has been with obesity, where people who have successfully lost weight have been used as mentors to people who are obese (in Skelmersdale) and of non-smokers as mentors in areas where there are a high number of smokers (Salford). Some use has been made of geodemographic/market segmentation software (such as Mosaic) to characterise local populations at a fine spatial scale. Much of this work has proceeded on a 'patch' or small population basis and is still in its infancy, it being widely acknowledged that systemic, population-wide effective approaches have not yet been achieved. The Transition Alliance concluded that 'There is real unease about how to amalgamate qualitative intelligence with quantitative data' and has prioritised the need for exemplar 'strategic assessments where there is national data, local data, and local qualitative material which has to be amalgamated and interpreted'.

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[135] Transition Alliance. Discussion about Asset Mapping and the JSNA. 2011 (November). Accessed at: http://www.transitionalliance.co.uk/phocadownload/JSNA/asset%20mapping%20-%20notes%20from%207%20nov%20discussion.pdf

[136] Improvement and Development Agency. *A glass half-full: how an asset approach can improve community health and well-being*. London: IDeA, 2010 (March).

[137] Nelson B, Campbell J, Emanuel J. *Development of a Method for Asset Based Working*. CPC and NHS North West, 2011 (March).

Methodologies for developing community asset mapping processes are still in an early stage of development. The Young Foundation and IdeA's Local Wellbeing Project is testing out practical ways of measuring individual and community well-being and resilience. A report from Phase 1 has been published by the partners: *Local Wellbeing: Can we Measure It?* (2008). Phase 2 is focusing on how data on well-being and resilience can be gathered and used by decision-makers in local areas. The project is developing a model of resilience and well-being, both at the community and individual levels that will support policy making and local resource prioritisation; demonstrating how existing data can be used to measure levels of local well-being, placed firmly in the context of comprehensive area assessment; and demonstrating how measuring well-being and resilience can be targeted towards particular population groups to achieve a range of outcomes. This approach will clearly need to rely on survey approaches and some attempts to measure well-being at an individual level have already been incorporated into the Integrated Household Survey (the only government survey that can yield actual or modelled estimates for higher tier local authorities).

APPENDICES

Appendix 1: Membership of the Data and Research Working Group of the Inclusion Health Board

Peter J Aspinall, Emeritus Reader in Population Health, Centre for Health Services Studies, University of Kent

Matthew Brindley, Policy Manager, The Traveller Movement

Rachel Coffey, Research Manager, Homeless Link

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

Professor Peter Goldblatt, Deputy Director, Institute of Health Equity, University College London

Dr Andrew Hayward, Reader in Infectious Disease Epidemiology, University College London

Adrian Hegenbarth, RCGP Social Inclusion Research Fellow, CIRC

Dr Bobbie Jacobson, (Chair), Hon. Senior Lecturer, Institute of Health Equity, University College London

Helen Mathie, Head of Policy, Homeless Link

Dr Joanne Neale, Reader in Qualitative and Mixed Methods Research, King's College London

Professor Jennie Popay, Professor of Sociology and Public Health, Lancaster University

Appendix 2: Selected JSNAs examined

Local Authority	Priority groups included	Sources
Sunderland 2011	Migrants (including asylum seekers)	Questionnaire survey of Primary Care Trusts
Nottingham City April 2010	Asylum seekers, refugees, and migrant workers	GP practices: Locally Enhanced Service
Newcastle 2008	Asylum seekers and refugees	Questionnaires after decision
Cambridgeshire 2011	Gypsies and Travellers	Local and national evidence
Surrey 2011	Gypsies, Travellers, Roma	GRT strategy documents
Slough 2011-12	Homeless	No fixed abode postcode
Devon 2011	Homeless	No fixed abode postcode
Cambridgeshire 2010	Homeless	No fixed abode postcode; Supporting People data;
Westminster July 2010	Sexual health needs assessment	Contacts with specialist services
Surrey October 2011	Sex workers	Team contacts
Bristol June 2012	Sex workers	Police estimates
Calderdale 2012	Sex workers	No records cited
Nottingham April 2009	Sex workers	Contacts with specialist services; police estimates
Croydon 2010-11	Sex workers	

Appendix 3: Glossary

Asylum seekers: In the UK asylum seekers are individuals who claim to be refugees who are waiting for a decision from the Home Office on their case. They will have lodged an application for protection on the basis of the Refugee Convention or Article 3 of the ECHR.

Gypsies and Irish Travellers: Gypsies and Irish Travellers are racial or ethnic groups as defined by the Race Relations Amendment Act. It is now regarded as good practice to capitalise the 'G' and 'T' in written references, thereby showing respect to group members. The terms used by the 2011 England and Wales Census are 'Gypsy' and 'Irish Traveller'. The Annual School Census uses the terms 'Gypsy or Roma' and 'Travellers of Irish Heritage'.

Homeless people: For the purposes of identifying vulnerable homeless people in this report, use has been made of the Office of the Chief Analyst's definition of the vulnerable homeless, that is, people sleeping rough, people sleeping in a hostel, and people in insecure or short-term accommodation, such as in a squat or on a friend's floor. The statutory homeless are also included though their health needs are less high.

Refugees: Refugee status is awarded to someone if the Home Office decides that they meet the definition of refugee as described in the 1951 Refugee Convention. A person with refugee status is also granted the immigration status Limited Leave to Remain in the UK. Limited Leave to Remain has a time limit of up to 5 years.

Sex workers: This term encompasses those men, women, and transgender persons working on the streets, and in such settings as massage parlours, flats, and as part of an escort service, to the exclusion of the wider sex industry, where the motive for sex is money.

Vulnerable individuals/groups: The concept of vulnerability is a contested term but used in this report to describe individuals/groups who experience disadvantage, marginalisation, social exclusion, and frequently disempowerment. All such groups suffer the double disadvantage of experiencing inequality in the context of the wider population (such as poorer health outcomes and inequalities in the determinants of health) and difficulty in accessing health services in general and especially primary care. The concept is not used as a simplistic label to describe a 'state of being' experienced by individuals/groups who are construed as passive victims of external forces[138].

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[138] For a useful discussion, see Popay J, Povall S, and Mathieson J. 'Defining key concepts' (paper presented to the Data and Research Working Group).