

Research to achieve actionable insight and intervention recommendations for Gypsy and Travelling Communities

A report for NHS Mid Essex

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Summary

Summary

Aims and objectives

As part of an ongoing programme of exploratory work with hard-to reach groups amongst its residents, NHS Mid Essex commissioned Ipsos MORI to undertake social marketing research with Gypsies and Travellers living in the local area. This research aimed to explore the health experience, healthcare needs, and access to NHS services of this marginalised group in order to provide actionable recommendations for interventions to improve their health and wellbeing.

Methodology

This research project was conducted in three stages; firstly a review of the available literature to give a national context to health issues faced by Gypsies and Travellers across the country, and to highlight best practice interventions with these groups elsewhere in the UK. Secondly, a series of interviews were held with key stakeholders from a range of public and voluntary sector representatives with direct experience of working with local Gypsy and Traveller communities. These interviews aimed to gain a more local perspective on how national findings 'translate' into the experience of Gypsy and Traveller groups in Mid Essex, and to explore initial thoughts about current and potential interventions. A steering group was also created involving many of these individuals to guide the recruitments, materials and reporting for this project.

Finally a series of in-depth interviews was conducted with 28 men and women from a range of age groups and including people from both Irish Traveller and English Gypsy origins. An interview approach was chosen rather than holding discussion groups, giving the well-documented importance of privacy within these communities. Researchers conducting the interviews were also gender matched to respondents to take account of cultural taboos associated with conversation about personal health across the gender divide. The interviews included families living on local authority run sites, private sites and in 'bricks and mortar' housing, as housing conditions and levels of mobility have been demonstrated to have a significant effect on health and healthcare access for these groups. Unfortunately, the researchers were not able to conduct interviews with those living in roadside or unauthorised encampments, but these are believed to be relatively few and far between in the Mid-Essex region, especially at the time of year this research was conducted.

Findings from the research

a) Literature Review

An analysis of the available literature highlighted a number of key health concerns for Gypsy and Traveller groups in the UK. Previous research has shown a high degree of health inequalities, indeed, some assert health inequities (where inequalities are unjust and avoidable) between Gypsies and Travellers and the general population, beyond those seen in many other ethnic minority/hard-to-reach groups. Gypsy and Traveller groups are more likely to suffer from a range of long term conditions, mental health problems, and disabilities, and to care for people with these conditions than other groups in society. Life expectancy is low, and infant/maternal mortality are higher as are rates of infections and accidents. Uptake of preventative health services in particular is very low in this community.

Researchers posit a variety of explanations for this, including cultural reasons such as the value placed on independence, fatalism about illness and gender norms which can prevent access to services, or prevent the open discussion of health and lifestyle issues. The emphasis placed on the family, and a certain suspicion of outsiders can also affect willingness to seek help outside the community. Low education and literacy rates, and relative social isolation also limit access to information and health and local services. A number of systemic issues were also highlighted which can cause problems for Gypsy and Travellers accessing health care, including lack of permanent addresses, discrimination on the part of health care professionals, and a lack of awareness of the specific needs of this non-visible minority. Impermanent housing, evictions and social stigmatisation can also adversely affect mental health.

b) Stakeholder engagement

Stakeholders broadly felt that the national picture of Gypsy and Traveller health is broadly similar to the local situation in mid Essex. In addition to the issues highlighted above, stakeholders also emphasised problems associated with an unhealthy diet and a less active lifestyle, which in turn increase the risk of long term conditions. Smoking, alcohol and drug use were also flagged as significant problems on Gypsy and Traveller sites, although it is felt that these are often hushed up, or not considered as having serious health consequences. Stakeholders felt that many issues related to a lack of uptake of health services, stem from an unwillingness to discuss health openly, especially when it comes to reproductive health, screening and mental health concerns.

Whilst stakeholders recognise the concerns outlined in the literature about the lack of access to care by those living on the roadside, this is considered to be less of a problem than in

other areas of the country due to a better provision of local authority sites, and a more understanding approach taken by local authorities in the region to those who are more mobile. The local NHS is also thought to be increasingly cognizant of the cultural differences and needs of Gypsy and Traveller groups, for example accommodating lots of visitors to hospital or helping with form filling for the less literate. Stakeholders emphasised the importance of individual relationships of trust developed between Gypsies and Travellers and local health professionals in encouraging service uptake and reducing fear of discrimination.

c) Primary research

It became clear from individual interviews with Gypsies and Travellers of all ages and housing arrangements that the primary influences on their health were less strongly related to the provision of services, but more to larger structural, social and cultural considerations, as highlighted in previous sections. Observational work on sites and the comments of Gypsy and Traveller residents demonstrated the significant impact of environmental factors, such as an inability to control neighbours on local authority sites, vermin and dirty conditions on sites, unsafe roads and a lack of public transport all contribute to a variety of health concerns.

Women in particular are restricted in their access to local services and healthy food and exercise by a lack of transport and the isolated location of many sites – this has a knock-on effect on their children. Women and men were observed to have very different attitudes to their health- the cultural emphasis on men to be stoical, and long hours of heavy manual work off-site restrict access to healthcare services and expose men to a range of health and safety concerns. Women play a key role in passing on health information and attitudes to children and looking after the wider family – this includes providing care for elderly relatives and the disabled. They appear significantly more proactive in seeking care than men.

Mental health concerns (associated with stress and frequent bereavements) were high in both gender groups, although women are more willing to discuss these and provide support to each other than men. Alcohol use and abuse is clearly a man's issue, but anecdotally seems more prevalent in the English Gypsy communities than amongst Irish Travellers. Smoking is a problem for both genders, and includes pregnant women; awareness of the impacts of unhealthy lifestyle choices on health is low for everyone.

Access to services appears on the surface to not be a major issue, especially for housed Gypsies and Travellers who often live close to GP surgeries and other amenities – in fact this is often cited as a key benefit of moving into 'bricks and mortar'. All the Gypsies and Travellers we spoke to had registered with a local GP and were able to see them when needed. Issues associated with accessing care appeared to stem more from cultural issues

such as not wishing to discuss 'women's problems' with a male doctor, and avoiding seeking treatment until a condition becomes acute/urgent. Access to preventative health services is clearly low for the latter reason also, as well as a lack of awareness of the services available. None of the participants were aware of services such as NHS Direct, but were enthusiastic about its potential. Some concerns were raised about a lack of understanding on the part of doctors and receptionists of Gypsy and Traveller culture, such as having lots of relatives visiting, or a lack of tolerance with literacy problems, but generally these were based on the experience of others rather than participants' own experience.

Recommendations for interventions

Ipsos MORI has recommended a number of interventions which might have an impact on the health-related behaviours of Gypsy and Travelling communities in Mid Essex. Some of the points which we feel are the most crucial to keep in mind when developing interventions for the Gypsy and Traveller communities in Mid Essex are:

- The central role of women in the health of the family
- The importance of hearsay and word-of-mouth for circulating messages
- Poor levels of literacy in the Gypsy and Traveller communities

The interventions recommended are largely focussed on:

- Improving lifestyle and health-related behaviours, for example using incentive schemes
- Improving access to services, for example using mobile units to provide some services and enhancing transport to and from services
- The structural changes required to promote healthy lifestyles and good access to services, with the overarching aim of reducing health inequalities.

Introduction

1. Introduction

1.1 Aims and objectives of the research

NHS Mid-Essex has responsibility for improving the health and well-being of the Mid Essex population. It also aims to empower people to take control of decisions about their health and well-being and proactively prevent ill-health. NHS Mid-Essex is keen to establish a process that engages with the local population and can influence positive behaviour change using social marketing techniques.

NHS Mid Essex approached Ipsos MORI to engage Gypsy and Traveller communities in research which would lead to interventions to help reduce health inequalities within the region. To do this, a research programme was developed to provide a better understanding of current attitudes towards health, health related behaviour and access to services amongst the Gypsy and Traveller populations in Mid Essex. Specifically, the research aimed to:

- Provide an overview of the current health behaviours of Gypsy and Travelling communities living in the NHS Mid-Essex area;
- Explore the experiences of Gypsy and Traveller communities who are accessing and/or using local healthcare services;
- Explore the values, barriers, expectations, incentives, dis-benefits and benefits of local healthcare services from the Gypsy and Travelling community perspective and experience; and
- Explore the experiences and views of healthcare professionals involved in the delivery of services to Gypsy and Traveller communities living in Mid Essex.

The outcomes of the research, as presented in this report, will be used to help design and test interventions and services that will respond to the health needs of Gypsy and Traveller communities in Mid Essex. Specifically, NHS Mid Essex will use this information to determine:

- How Gypsy and Traveller communities can be encouraged to adopt a healthy lifestyle and increase the use of health services, both universal and targeted;
- What would lead to an increase in the numbers of Gypsy and Travelling communities accepting a new lifestyle behaviour and/or to access primary care services / and/or health improvement services; and

- What interventions would encourage Gypsy and Traveller communities to accept a new behaviour and/or access primary care services and/or health improvement services.

1.2 Audience

According to the Race Equality Foundation (Matthews: 2008), the UK currently has a population of 300,000 people¹ who are classed as ‘travelling communities’; this community is not homogenous, but includes:

- Romany Gypsies (or Roma)
- Scottish Travellers
- Welsh Travellers (or Kale)
- Irish Travellers
- New (Age) Travellers
- Bargees (or Boat Dwellers)
- Showpeople and Circus People

For the purposes of this project, and due to a scarcity of research, which would allow for a more detailed breakdown of issues and initiatives between these groups, we will refer throughout to ‘Gypsy and Traveller communities’. It should be noted, however, that our study, like most others, excludes ‘occupational Travellers’ such as New Age Travellers, Bargees, Show People and Circus People who have opted for an alternative lifestyle but are not (usually) of the same cultural background or ethnic origin as other Gypsy and Traveller groups.

As well as the marginalised groups themselves, it was considered important to engage with a variety of audiences involved in providing and/or facilitating access to healthcare services to Gypsy and Traveller communities. Specifically, these target audiences were:

- Gypsy/Traveller site managers;
- Primary Care staff, clinical and non-clinical;

¹ As Gypsies and Travellers are not included in the Census as a separate ethnic minority category, this is an approximation only.

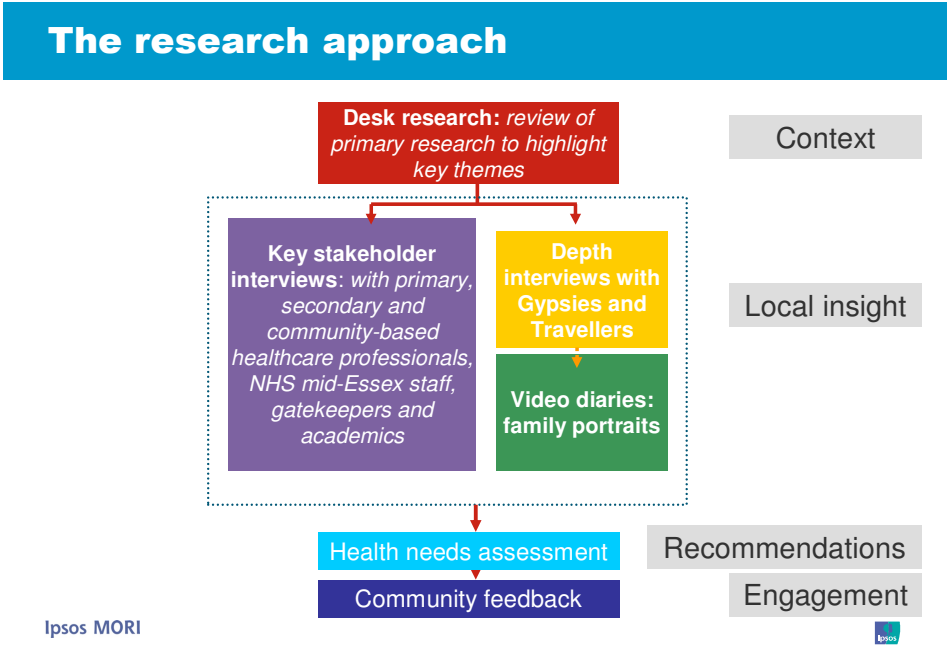
- NHS Mid-Essex Health Provider Services e.g. Health Visitors;
- Providers of preventative/screening/healthy lifestyle services;
- Council (County and local) staff involved with Gypsies & Travellers; and
- Community development workers or groups (e.g. MENTER).

In the next section we will give more detail on the methodologies used in this research project, as well as the challenges inherent in ensuring participation from the key audiences described above.

Methodology

2. Methodology

Our approach to this research is illustrated in the graphic below. The first stage of research involved a review of current academic and grey literature to understand the ‘national picture’ relating to Gypsies and Travellers’ relationship with the health system, and to discover examples of healthcare interventions with this population. The second stage was primary research and was designed in two strands. Strand one involved a series of key stakeholder interviews to gain insight into local-level health-related issues affecting Gypsies and Travellers. Strand two involved depth interviews and participant observation research with Gypsies and Travellers. A steering group was also created to include key stakeholders from the local authority and NHS, as well as voluntary sector organisations representing the Gypsy and Traveller community. This group met regularly to oversee the development of the content and methodology for the research.



2.1 Literature Review

The first stage of this project was to conduct secondary research of existing literature on the subject. This research helped to inform the next stage of (primary) research, involving in-depth interviews with local health and travelling community stakeholders, as well as in-depth interviews and ethnographic (observational) work with Gypsy and Traveller communities themselves. This secondary literature review helped to direct and focus the research in order to ensure that existing knowledge was fully utilised and built upon.

The scope of the desk research was:

- Identification of key health determinants for Gypsy and Traveller communities and their experiences of using the NHS.
- Identification of previous interventions to improve access to health services – both those that have and have not worked – specific to Gypsy and Traveller groups.

The literature review involved identifying sources, developing detailed search terms, defining inclusion and exclusion criteria (such as location-based findings and work produced since a certain date) and deciding on quality assessment criteria. A simple data extraction tool was then developed to record each study that meets the criteria and to give a measure of relevance, reliability and validity. Once literature was collected, results were synthesised, key ideas and project outcomes summarised and key areas of difference and similarity explored.

2.2 Stakeholder work

In order to support this research project, a steering group was set up to advise and guide the research, and ensure that challenges were dealt with in an ethical, sensitive and efficient manner. The steering group met at strategic points during the setup and fieldwork stages.

The steering group was composed of around 6-10 people, including:

- Staff from NHS Mid-Essex;
- Primary and community health care providers – GPs, health visitors;
- Representatives from relevant community groups
- Representatives from other local service providers with a remit to provide services to Gypsy and Traveller groups, such as the Traveller Education Service and housing/site services

The second stage of stakeholder work involved in-depth interviews with local health and travelling community stakeholders, including:

- Health visitors
- Local Authority Gypsy and Traveller service staff
- Gypsy and Traveller community activists/volunteers
- GPs
- The Traveller Education Service
- MENTER

The aim of the Stakeholder interviews was to test themes found in the literature review and investigate whether they hold true in Mid Essex, rooting the research more specifically in the local context. It ensured that the programme of primary research did not cover old ground or propose interventions already tried unsuccessfully in the area. These interviews enabled the research team to access the extensive frontline knowledge such stakeholders had about Gypsies and Travellers' health behaviour and experiences and highlighted the key problems and challenges that current healthcare professionals and their patients encounter when trying to reach Gypsies and Travellers with healthcare messages.

2.3 In depth interviews with Gypsies and Travellers

The chosen methodological approach for this strand of the research was individual, or paired in-depth interviews. Whilst initially we considered using an approach which included single gender discussion groups on particular Gypsy and Traveller sites, discussion with the steering group and insight from the literature review suggested that this would not be the most appropriate methodology to ensure detailed and accurate results with this audience. Given the high value placed on privacy within the Gypsy and Traveller community, we felt it would be unlikely that participants in discussion groups would feel able to discuss personal health concerns. In addition, given the informal attitude of these communities, we felt it would be difficult to maintain time-keeping and ensure continued participation of key individuals in the group, without having other onlookers and contributors intervening. Suitable venues for these groups on Traveller sites were also not forthcoming.

2.3.1 Recruitment approach

To recruit members of the Gypsy and Traveller communities to take part in this research, we used two main approaches:

1. Contact authorised sites (recorded in the 2008 Caravan Count²) via Local Authority Gypsy and Traveller liaison officers and using advice and support from voluntary and public sector organisations which act to support marginalised groups such as Gypsies and Travellers. These included Essex Traveller Education Services, the Health Visitor service within the NHS, and the Cambridgeshire/Essex MENTER office.
2. Using relationships built during the research with Gypsy and Traveller communities (and organisations/individuals which work with them) to find other, more 'hidden', individuals and families who may live outside registered sites (for example, on unauthorised sites or in 'bricks and mortar' homes). This method of recruitment is known as 'snowballing' and can be very successful in finding hard-to-reach audiences and people who live outside established networks.

By engaging with Local Authority officers and charities set up to promote the views and needs of Gypsies and Travellers we were able to communicate in advance about the research with communities through familiar and trusted contacts. Where possible, we asked our contacts to make it known that we would be coming to a site on a particular day. We then recruited respondents by telephone face-to-face on the sites, though they were offered the opportunity to call our research team before their interview if they had any questions or concerns about the research.

We aimed to speak to a wide range of Gypsy and Traveller individuals, male and female, from a variety of age and ethnic (English Gypsy/Irish Traveller) groups and from a range of living situations, to get a good 'picture' of the difference in lifestyle and attitudes within the communities. There was a smaller target sample size for Irish Travellers, as they represent a minority in the local Gypsy and Traveller population in Mid Essex. Housed Travellers were much more difficult to find, and as a consequence the final sample achieved is relatively small.

² The most complete list of sites detailing the number and location of caravan sites is collated by Communities and Local Government in their bi-annual Caravan Count. This consists of information about Gypsy/Traveller caravan sites given to CLG by Local Authorities and Registered Social Landlords. All of these sites are legal and on public land. The 2008 Caravan Count lists six authorised sites in Mid-Essex (2 in Braintree, 2 in Chelmsford and 2 in Maldon) including an estimated total of 72 caravans. This list was supplemented by additional information from the local authority regarding the number of private sites in Mid Essex, including those with planning permission and those without.

Our final completed interviews per subgroup were as follows:

Age		Gender	
18-25	4	Male	12
26-40	8	Female	15
41 – 60	9		
60+	6		
Living situation		Ethnic background	
Housed	6	English Gypsy	22
Local Authority site	12	Irish Traveller	5
Private site	9		

2.3.2 Methodological challenges

This section provides some additional insight into the fieldwork process during this research, as we felt that it would be useful to discuss some of the challenges of working with a Gypsy and Traveller audience in a research context. This may be informative for others wishing to conduct further research with this community in Mid Essex, or indeed elsewhere in the country. We hope that it will also be useful for health professionals and others who provide services to Gypsy and Traveller communities when designing outreach and other interventions.

Locating the target audience

Accessing an itinerant population

One of the biggest challenges we faced in completing the fieldwork was to find and include roadside encampments (also called unauthorised sites) in the sample. Mid Essex does not appear to have many of these types of sites, as explained by the Essex County Council Traveller service, and a policy of moving-on unauthorised sites after a short period of time, makes locating them difficult. Recording information on these sites, or their location, is very difficult and the location information which is collected soon becomes out of date.

Furthermore, the more mobile groups in the Gypsy and Traveller population often begin their travels to areas of employment where they will remain for the summer in April and May (when the fieldwork was conducted³).

Remoteness of sites

³ The requirement to complete the fieldwork in time for the Health Needs Assessment meant there was limited choice in when the fieldwork was carried out.

Many Gypsy and Traveller sites in Mid Essex are located in quite rural settings, without local public transport. Sites are rarely signposted and are frequently along small country lanes and therefore can be difficult to locate.

Housed Travellers as a 'hidden' group

To speak to housed Travellers we used the technique of 'snowballing', asking people we interviewed if they knew Gypsies and/or Travellers who live in 'bricks and mortar' homes who might be interested in taking part in the research. This is a standard approach to recruitment in qualitative research, particularly when working with 'hard to reach' groups. Among the housed Gypsies and Travellers we interviewed however, they commonly had many friends and family living on sites but knew fewer people living in homes living within Mid Essex.

It also seems to be the case that sometimes people move into houses to escape their previous life (for instance domestic violence or suffering from discrimination) and therefore wish to keep their identity as a Gypsy or Traveller hidden. Some interviewees acknowledged that they would sometimes choose not to openly divulge their ethnic and cultural background to their neighbours and their children's schools. In these cases, the Traveller Education Service was invaluable in helping to identify housed Gypsies and Travellers. However, it is likely that many housed Gypsies and Travellers 'disappear' into the general population, which makes it very difficult to target them for this type of research or interventions.

Cultural challenges

Health matters are not often discussed openly within Gypsy and Traveller communities (particularly with men). While we did not find this was as marked as suggested by the literature review (perhaps because of the relatively privileged situation of Gypsies and Travellers in the Mid Essex area in terms of permanence, site provision and interaction with services), it presented a barrier to discussion of personal health and the more sensitive topics such as sexual health.

We encountered some individuals who felt that they would not be suitable for the research because they did not use the doctor or other health services. Whether or not this was the truth, it illustrates a reluctance to discuss matters of health and could indicate that the most disengaged from health services have not been fully represented in this research.

Logistical challenges

Lack of private space

Gypsy and Traveller sites vary considerably in their appearance, layout and facilities. While some involve brick-built homes which have been there for decades, with electric fencing and a great deal of space, others (particularly Local Authority sites) can be much smaller, with no outdoor communal space and caravans located in close proximity to others. Caravans made it difficult to ask individuals about personal matters as they often have open doors and neighbours will regularly arrive unannounced. Moreover, the caravans themselves are shared spaces where families occupy small spaces together. Discussions around sensitive matters, such as sexual health or domestic violence, were difficult as they might be interrupted or overheard.

Timekeeping

Setting times to meet with someone was not always a straightforward process as the concept of time can be quite fluid for Gypsies and Travellers, and with literacy being poor people did not tend to keep written reminders of appointments.

Men predominantly work off-site and are often self-employed so do not necessarily follow a regular nine-to-five working day. Men of working age are seldom present on sites during the day and, when they are, may have limited time before they need to leave for work again.

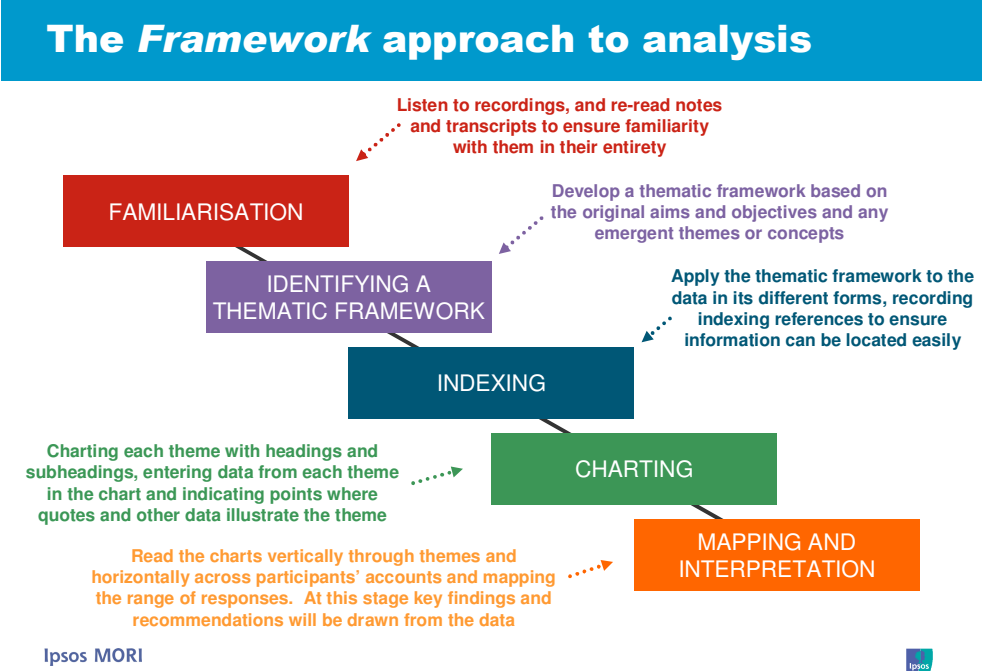
The use of telephone landlines is patchy, and we even discovered one telephone number (housed) which did not allow incoming calls. Because of this, arranging interviews could be time-consuming and required a flexible approach. Site managers were excellent for obtaining contacts, but introduced another layer of communication to navigate.

2.4 Our approach to analysis

Analysis and reporting are the key elements in the successful delivery of programmes of research, and need to stand up to public scrutiny. Our approach to analysis in this report is underpinned by an approach called *Framework*. *Framework* is explicitly geared towards generating policy and action-oriented findings, and is a content analysis method which involves summarising and classifying data within a thematic framework. There are five key stages undertaken during the *Framework* approach.

Throughout the research brainstorming has been built into the process, where the core team met to discuss the findings regularly, and immediately after carrying out fieldwork. These meetings were relatively unstructured, the idea being to get as much out of the data as possible. At the end of fieldwork a more structured workshop was held where findings were

discussed in order to develop a thematic framework for presenting the findings and actionable recommendations for the development of interventions.



The following chapters present the findings of the research.

Literature Review

3. Literature Review

3.1 General background to the Gypsy and Traveller population

There is a growing body of literature which documents the health behaviours and inequalities faced by Gypsies and Travellers in the UK. The Gypsy and Travelling communities are found to be amongst the most – if not *the* most - marginalised and disadvantaged groups in society, and health indicators highlight the seriousness and scale of the challenges that must be addressed. Van Cleemput (2007b) argues that Gypsy and Traveller communities are not only subject to health inequalities, but in fact are victims of “*health inequities*”, which she defines as “*where the inequalities are unjust and avoidable*”. She notes three major areas in which Gypsy and Traveller communities suffer from health inequities, namely:

Health damaging behaviour where the degree of choice of lifestyles is restricted; exposure to unhealthy, stressful living and working conditions; and inadequate access to essential health and other public services.
(European Partners for Equity in Health: 2006)

From this literature review the following themes have emerged:

- Social problems with access to healthcare
- Cultural beliefs about health which affect take-up of services
- Environmental health concerns associated with Gypsy and Traveller sites
- Mental health issues rooted in restrictions on mobility and discrimination
- Problems with maternal and infant care
- Problems with care of Gypsies and Travellers with long term or terminal illnesses

3.2 Health status of Gypsy and Traveller communities

Assessing the health status and dynamics of Gypsy and Traveller Communities has until recently been a relatively difficult exercise, due to the fact that Gypsies and Travellers are not included in the national Census or the Health Survey for England. Barton (2004) argues that this lack of monitoring causes this already ‘invisible’ minority group to become even further out of the sight and reach of the state. Very few PCTs and SHAs currently collect monitoring data which includes Gypsies and Travellers as a specific ethnic minority, despite the fact that

Romany Gypsies and Irish Travellers are a recognised minority ethnic group under the Race Relations Act 1976. This makes an assessment of their needs difficult (Matthews: 2008). There are, however, a number of PCTs that are making good progress on this issue – please see Section 4 for a more detailed discussion of these initiatives.

Many assessments so far have been limited to very local areas and are not representative of the broader Gypsy and Traveller population. There are a small number of studies published in the last five years however (Parry et al: 2004; Parry et al: 2007) which specifically aim to address Gypsy and Traveller health needs and status and are statistically robust enough to allow for comparison against other population groups in the UK. Health data from Ireland (see, for example, Pavee Point: 2005) and smaller localised studies (see data from Cambridgeshire PCT: 2007 and Chelsea and Westminster PCT: 2005, for example) will also be used for indicative purposes, but further research would be required to establish whether trends are the same throughout the UK.

There also exist a number of qualitative studies around the health-related beliefs of, and usage of health care services by Gypsy and Traveller communities, which will be used to provide insight into the more esoteric aspects of these communities' understanding of and approach to health, and to suggest ways in which health professionals and commissioning bodies could approach this community in a more culturally appropriate and effective manner. Please see the appendix to this report for a full listing of the references referred to in this review.

3.3 The current state of health of the Gypsy and Traveller population

As a group, the overall health status of Gypsy and Traveller communities is poorer than the general population, and indeed poorer than other socially deprived groups and other ethnic minorities (Parry *et al.* 2007). Gypsies and Travellers are significantly more likely to have a long-term illness or disability, and more commonly report chest pain, respiratory problems, arthritis, anxiety and depression (Van Cleemput: 2007a). In the 2001 census, the proportion of the population overall reporting limiting long-term illness was 18%; the proportion of Gypsy and Traveller groups reporting this in 2007 was 42%. Significantly more Gypsies and Travellers were the main carer for someone with a long term health condition or disability than the general population, and they were more than four times as likely to care for someone below the age of 65 (Parry *et al.* 2007).

Power (2005) cites research which claims that the average life expectancy of a Traveller man is ten years shorter than a settled man's, and Traveller women live on average twelve years less than settled women. This is a very wide gap even compared to that between lower socio-economic groups and more affluent groups in the UK. Parry et al (2007) also found that Gypsies and Travellers had more problems with mobility, self-care, usual activities, pain or discomfort as assessed using the EuroQoL-5D health utility measure⁴, and a higher overall prevalence of reported chest pain, respiratory problems, arthritis, miscarriage and premature death of offspring. The scale of the difference on the EQ-5D can be understood in terms of 'quality of life years'; assuming the same life expectancy, where the general population enjoy 62 quality years, Gypsy and Traveller groups enjoy only 56.

Although no statistically significant inequality was reported in diabetes, stroke and cancer prevalence between Travelling and settled communities in Parry et al's (2007) study, this may be affected by the small sample size. Studies on the prevalence of obesity and related diseases (type two diabetes, metabolic syndrome and CVD) in Slovakia found that Gypsies had higher BMI's, higher prevalence of type two diabetes and hypertension (Vozarova de Courten: et al 2003; Dolinska et al: 2007), although it is unclear whether these issues also affect those of Traveller descent.

Other possible factors which could lead to under-reporting of any differences may include high premature death rates amongst Travellers, and the fact that cancer and type II diabetes tend to be "silent" diseases until their later stages. These might lead to underreporting if understanding of symptoms of these conditions is low and stoicism and concerns for privacy are high (see Section 3.3. for a more detailed exploration of these cultural issues).

Other studies have reported a high incidence of health problems that can be attributed to adverse environmental conditions such as gastroenteritis, upper respiratory infections and ear infections (Taylor: 1991, Lawrie: 1983 and Batstone: 1993), although these studies are based on local primary care practitioners' accounts rather than large scale epidemiological data collection.

Another study in Sheffield showed statistically and clinically significant health differences between Gypsies and Travellers and the local population, which are strongly associated with smoking and with frequency of travelling (Van Cleemput and Parry: 2001). Significantly more

⁴ EQ-5D is a brief, generic health status measure (sometimes described as a health-related quality-of-life measure). It defines health in terms of five dimensions, (mobility, self-care, usual activity, pain or discomfort, anxiety or depression) with each rated at one of three levels, (no problem, some problem, extreme problem). This scale is standardised from 0 (representing death) to 1 (perfect health), although some states are rated as "worse than death" (less than 0). As a descriptive measure of health, the

Gypsies and Travellers were current smokers than the general population, and nearly five times as many Gypsies and Travellers reported symptoms of chronic bronchitis than the general population in Sheffield, and over twice as many reported asthma-like symptoms or symptoms of angina (Parry et al: 2007).

Localised studies conducted by Health Promotion Teams also raised concerns over rates of dental decay and arthritis on Gypsy and Traveller sites (Chelsea and Westminster PCT: 2005), as well as low uptake figures for cancer screening and family planning services (Cambridgeshire PCT: 2007).

3.4 The influence of Gypsy and Traveller culture on healthcare beliefs and access to services

There are a number of aspects of traditional Gypsy and Traveller social structure and cultural belief systems which have a bearing on health care access and uptake of services. For example, Lehti and Mattson (2001) described Gypsy and Traveller society as being based on a strong respect for men and elders' views, and placing high value on independence, stoicism and self-reliance (particularly in men). Van Cleemput et al (2007b) and the Sussex Traveller Health Project (2008) feel that this could be a potential explanation for the gender division in take-up of primary care services described in many studies. For example, Clohessy and McGinley (2002) found that only 37% of Traveller attendees at a clinic in Ireland were men, compared to 63% women.

Health visitors for Cambridgeshire PCT (2007) and Chelsea and Westminster PCT (2005) have also noted that women were very reluctant to discuss health issues with a health professional of the opposite sex, and female researchers such as Jesper (2008) and Dion (2008) found it very difficult to access male respondents. Worries about a lack of gender matching may also hinder take-up of health services, where Travellers have restricted choice, or are not aware of their right to choose a GP or HCP of their own gender.

The value placed on having a close extended family can also play a role in health care access – for example, it was felt that terminally ill patients were better off being cared for by their families and complex issues such as substance misuse and mental health problems are best dealt with 'in the family' (Jesper et al: 2008). This also affects patients' willingness to remain in the healthcare system after they have been admitted. Van Cleemput (2007b) describes a situation where a Gypsy patient discharged themselves early from hospital due

EQ-5D is a multi-attribute health utility measure, allowing the calculation of quality adjusted life years (QALYs) as a standard metric across different groups.

to restrictive visiting rules which prevented his family of fourteen from visiting him when they wished to and in large numbers.

The emphasis placed in Gypsy and Traveller culture on independence also affects the way children are brought up, and the level of control parents have over their offspring. Dion (2008) noted that many Gypsy mothers said that they had real difficulty in refusing things to their children or restricting their activities. Dion argued that this can result in a lack of boundary setting which can mean that 'the child may not develop the crucial ability to self-regulate their behaviour as they are faced with more health-threatening situations', such as overeating, smoking, alcohol or substance misuse.

Dion also feels that it may also present an explanation of the widely documented low school attendance rates amongst Gypsy and Traveller communities (see, for example ESTYN: 2005). Low attendance also means that children miss out on health education opportunities provided in the educational setting. Whilst parental discipline is not the only way in which children develop boundary mechanisms, the different ways in which children learn health-promoting or health-damaging behaviours in this community should indeed be taken into account when designing preventative health campaigns for them.

Jesper et al (2008) also noted specific cultural norms relating to what is 'healthy' amongst the Gypsy community which can cause problems in a healthcare setting, especially in a hospital environment. For example, many participants in her study did not like being confined to hospitals, especially where they were in closed rooms with no windows (what she calls the 'bricks and mortar syndrome'). The Ormiston Children's and Families Trust (2008) takes this even further, stating that in Traveller culture, *"lying in a hospital bed is seen as synonymous with death"*.

The Ormiston Children and Families Trust (2008) have also discussed many other beliefs relating to cleanliness that are specific to the Gypsy and Travelling community and can mean that they find it difficult to remain in an environment which does not share these values. For example, many Gypsies and Travellers will use separate bowls for washing dishes, clothes, and food preparation, as well as different parts of the body. They may be unwilling to eat hospital food, preferring to eat food brought in by friends and relatives because they know that this food has been prepared correctly. Gypsies and Travellers might also feel very uncomfortable in clothes and sheets provided by the hospital as a result of these cultural views around cleanliness.

3.5 Health care professionals and their relationship with Gypsy and Traveller patients

Many authors report incidences of mistrust, miscommunication, and even discrimination in communications between Gypsy and Traveller communities and health care professionals. These problems can lead to a lack of uptake of health services and low quality of care. It has been found that many minority groups find themselves in this situation, which Appleby and Deeming (2001) call the 'inverse care law' – those most in need of health care services due to higher incidence of health problems in fact get the least care.

In part due to a lack of monitoring data and an understanding of travelling communities, most PCTs do not have specific health care staff assigned to Gypsy and Traveller sites. This appears to reflect a more general lack of statutory support for Gypsy and Traveller issues in the health sector. Many health workers assigned to Travelling communities must do their work in the Gypsy and Traveller community in conjunction with interventions with more visible ethnic minority groups, homeless people and asylum seekers. This means that scant attention is paid to the Gypsy and Traveller community's very specific needs (Parry et al: 2004).

A number of authors point to reluctance by many GP practices to register Gypsy and Traveller patients (for example, see Parry et al., 2004). This is often attributed to concerns about a lack of uptake of services by Traveller communities leading to practices missing practice level targets on appointment waiting time, routine screening and immunisation. Although practices are technically not allowed to refuse a patient, according to Power (2005), some practices have been known to use the excuse of full doctors' lists in this situation to avoid registering a Gypsy and Traveller family whom they perceive to be likely to place high demand on health care resources.

Goward et al (2006) note a lack of cultural sensitivity displayed by primary health care professionals. Power (2005) suggests that many health professionals and health service managers fail to understand or even acknowledge the difference between Gypsies and Travellers and poorer segments of 'mainstream' society, and even consider them as similar to the homeless, which in his view can lead to a massive underestimation of Gypsy and Travellers' specific needs.

Power (2005) asserts that there is such a lack of understanding of Gypsy and Traveller communities by health care professionals and administrators that often the only way in which these communities can access care is to rely on the personal skills and influence of a

determined health worker playing the role of advocate. He describes many cases where health visitors have had to intervene on behalf of Gypsy and Traveller who could not make their accents understood to GPs, or had missed hospital appointments because they could not read the invitation letter.

Some even report bad experiences with practice receptionists who have refused to give them the same priority as other local people with permanent addresses (Jesper et al: 2008) or would only agree to register them as temporary residents, excluding them from services such as screening and immunisations (Power: 2005). Many of these families end up accessing walk in centres or A&E departments which limit the ability of HCPs to provide continuity of care. Some outreach services such as health visitors can go some way to plugging the gaps for advice or preventative services but cannot offer full services for those who are ill. Frequent changes of site, and a reliance on A&E means that proper health records are often not built up about Gypsy and Traveller families, resulting in a lack of follow-up which can increase the risk of misdiagnosis and a lack of management of long term health conditions in particular (Power: 2005).

The process of evicting Gypsy and Traveller groups from unlicensed sites can also lead to compromised health care access. Power (2005) draws attention to a lack of due care and attention paid to the health needs of Gypsy and Traveller groups by bailiffs. He describes cases where even heavily pregnant mothers have been 'moved on' without calling a health visitor to the site to assess their medical condition before carrying out the eviction. Although it is not clear from his study how prevalent this kind of behaviour is, it should be borne in mind by local authorities and PCTs working in strategic partnership to deliver health and wellbeing improvements for their residents.

Many sites are situated a long way from health and other services, compounding social barriers to access, and are often considered 'no-go' areas for ambulance and other health workers due to perceived security concerns, meaning that access even to emergency medical assistance may be restricted (Dion: 2008).

Lack of access is not only an issue for mobile families, however. Housed Gypsies and Travellers can also be reluctant to access health services due to a history of discrimination which fosters a lack of trust in authority figures, a mistrust of outsiders, and low expectations of services (Matthews: 2008, Jesper et al:2008). Persistently low levels of literacy and high levels of poverty amongst travelling groups exacerbate these issues. As is the case with many low-income groups, regardless of their ethnic background, many Gypsies and

Travellers cannot afford the time or transport to attend hospital clinics and often cannot read the details of prescription dosage and timing, leading to gaps in treatment regimens which can be life-threatening (for examples of this see Power: 2005).

3.6 Maternal and infant health

Whilst Parry et al's (2007) study did not show any significant differences between the wider population and Gypsy and Traveller women in terms of problems associated with pregnancy and childbirth such as pre-eclampsia or morning sickness, significantly more Traveller women experienced miscarriages than the general population (29% as opposed to 16%). Other studies, including the Confidential Enquiry into Maternal Deaths in the UK found that Gypsies and Travellers have 'possibly the highest maternal death rate among all ethnic groups' (Lewis and Drife: 2001). The Maternity Alliance (2006) asserted that this was related to difficulties in accessing antenatal services and a lack of continuity of care, especially amongst more mobile travelling women. Anecdotal evidence gathered by the Maternity Alliance and Power (2005) points to a few cases where forced evictions have been carried out without taking into account the health needs of pregnant women and new mothers.

Infant mortality rates amongst Gypsy and Traveller communities are some of the highest in the country. Neligan (1993) attributes many infant deaths to infections related to poor sanitation and clean water access. Other studies have reported low birth weight, a high child accident rate (Hajioff and McKee: 2000; Pahl et al: 1986), low immunisation uptake (Feder et al: 1993) and low usage of family planning services in travelling families, although the last of these may be partly explained by the strong Catholic beliefs of many, particularly Irish, Traveller communities (Power: 2005). Research suggests that low immunisation rates are linked to fatalistic notions of illness and the perceived role of luck involved in catching communicable diseases, combined with the notion that if a parent allowed a child to be vaccinated and they later become brain damaged the parent would be responsible (Edwards and Watt: 1997).

Dion (2008) highlights cultural beliefs associated with motherhood and childrearing which may affect the life chances and health outcomes of Gypsy and Traveller children. The Traveller women she spoke to were averse to talking about 'personal' health matters in public, especially in mixed gender contexts. Dion argues that this belief may at least partly explain very poor breastfeeding rates among Gypsy and Traveller women (as they consider it inappropriate for a man to see their breasts). There are also cultural beliefs around breastfeeding being an economic necessity rather than healthy: Travellers do not want to be

thought of by others as poor or unable to afford to buy formula milk (Travares: 2001). Children who are not breastfed are statistically more likely to be at risk of childhood diseases, obesity and other later life health complaints such as diabetes and heart disease (Isselman et al: 2008).

The social dynamics of the Gypsy and Traveller community can also influence the distribution of health related information and knowledge. Dion notes that a strong oral tradition, family networks, and the social isolation of the Gypsy and Traveller community mean that health information is passed down between generations and amongst female peers, which means that misconceptions are also passed down alongside useful information. She suggests that this may explain the lack of uptake of vaccines such as MMR amongst Gypsy and Traveller children which has also been noted in many localised studies (see Cambridgeshire PCT: 2007, and Chelsea and Westminster: 2005).

3.7 Travelling communities and chronic illnesses

Care for the chronically and terminally ill is another particular area of health care provision which requires specific improvements in cross-cultural understanding as well as the attitude of health care professionals in order to provide for the specific needs of Gypsy and Traveller communities.

Beliefs associated with certain types of potentially fatal diseases such as cancer, and with the effect of terminal prognoses on patients amongst Gypsy and Traveller communities can be very different from those held by the wider population. Whilst these beliefs are not necessarily held by all or even the majority of the Gypsy and Traveller community, both Van Cleemput (2007b) and Jesper et al (2008) noted the presence of culturally specific beliefs about cancer which were likely to affect willingness to accept treatment. For example, a number of respondents described two types of cancer; a male one, which 'puts out roots' and is likely to kill you, and a female one, which 'lays eggs' – you can freeze it for a while, though it can spread (but usually will not do so unless it is ruptured through an operation). It is also believed by some that exposing cancers to the air by undergoing operations can lead to metastases and death.

Van Cleemput et al (2007b) suggest that cultural beliefs about health can discourage presentation for screening or diagnosis until late stage symptoms are shown. They argue that many Gypsies and Travellers have a 'fatalistic' notion of health which means that an illness is something which is given to a person who has no control over it and is almost inevitable in later life. Jesper et al (2008) found evidence of a prevalent belief that imparting

bad news (such as a diagnosis of cancer) can diminish resistance or even kill a person through shock, and therefore patients should not be given such diagnoses. This type of attitude stands in stark contrast to ideas of encouraging personal responsibility for and engagement with health that is behind healthy lifestyle and preventative care initiatives (Dion: 2008).

Jesper et al (2008) note that those affected with potentially fatal diseases such as cancer are not currently well catered for within the NHS, partly due to a lack of continuity of care caused by mobility, partly due to a lack of knowledge of the hospice movement, and partly due to a lack of regard by HCPs for the desires of Gypsy and Traveller patients to spend their final days at home with family. Despite early research which claimed that in Gypsy culture death is linked to pollution and as such that ideally a Gypsy should die in hospital. Jesper in fact found that many Gypsy families expressed pride in the ability and strength of the family to cope with and provide support for terminally ill relatives outside of the hospital context.

3.8 Mental health concerns for Gypsy and Traveller groups

Parry et al (2007) note statistically higher incidence of anxiety and depression in travelling communities when compared to the rest of the UK population. Localised health needs assessments in Cambridgeshire (2007) and west London (2005) both found more than 50% of adults on particular sites suffering from some form of emotional disorder. Anecdotal evidence also indicates that alcohol and drug use are high in travelling communities; Matthews (2008) suggests that this is a coping strategy to deal with financial and emotional hardship, especially amongst settled Gypsies and Travellers. There are also concerns about high suicide rates in Gypsy and Traveller communities, but this needs further substantiation to establish a real sense of prevalence.

Others emphasise the importance of HCPs' understanding of cultural factors associated with mental health in Gypsy and Traveller communities. Parry et al (2004) noted that travelling groups attach a stigma to depression which can lead to hiding symptoms and reluctance to seek treatment. Treise and Shepherd (2006) confirmed this finding, noting that many of the Travellers they spoke to considered that things perceived to be shameful (such as substance misuse or mental illness) were best kept within the family. This is especially true amongst men, who, as discussed earlier, are encouraged to be stoical and self-reliant (Jesper et al: 2008). Bristol MIND's 2008 study also confirms this: whilst ideas such as 'nerves' and 'worries' were discussed openly, especially amongst women, the term 'mental' was viewed with suspicion, and was seen as being linked with madness.

Van Cleemput et al (2007a) draw attention to the effect of frequent evictions on the mental health of Travellers, which causes high levels of uncertainty and anxiety. The inability to control one's living arrangements, and the social unrest and violence which are often associated with evictions can have serious effects on the mental health of Gypsies and Travellers, especially children. Forced moves not only create fear and stress, they also compound a sense of alienation, as they impact on the ability to form friendships and increase a sense that 'nobody likes Travellers' (Warrington and Peck: 2005).

Settled Gypsies and Travellers can face mental health problems linked to social isolation: where they were used to travelling in extended family groups, the limited number of plots available on council sites, or the nuclear family basis on which permanent housing is allocated, means that it is rare for larger groups of relatives to be close to one another (Van Cleemput: 2007a). Limited choice in plot location and size on official sites does not allow for much privacy or opportunity to avoid difficult neighbours. In addition, when Gypsies and Travellers are allocated housing they are often subject to racial harassment which can add to stress and anxiety (Commission for Racial Equality: 2006).

Most authors argue that mental health problems are more commonplace amongst settled Gypsies and Travellers than their mobile counterparts. Women interviewed by Dion (2008) recounted dealing with stress, panic, anxiety and depression due to not being able to travel and contrasted these feelings with those experienced when they are travelling including 'the sense of freedom, being in the fresh air and being near to extended family'. Van Cleemput et al (2007a) asserts that this is particularly true for Gypsy children, who feel 'caged' by permanent housing and often resort to disruptive and offending behaviour as a result.

Van Cleemput (2007a) argues that the mental health issues related to housing are also compounded by a sense of injustice amongst Gypsy and Traveller groups:

Society does not value their culture and intends them to abandon their nomadic lifestyle. Therefore they perceive that they are seen as inferior through lack of entitlement to equal cultural rights that are afforded to other groups.

This then becomes a 'double bind' where Gypsy and Traveller groups feel socially excluded whether they try to pursue their traditional lifestyle (and therefore lose access to services and the right to vote for example) or whether they conform to societal pressures to adopt a more less active lifestyle (Morris and Clements: 2002).

Karlsen and Nazroo (2002) suggest that the belief that one is living in a society that will discriminate against you on ethnic grounds is health damaging in itself, noting that:

Negative emotions, including depression, anxiety and hostility, that can result from low social status, and related psychosocial factors, may not only lead to clinical mental ill-health but also to suppressed immunity, cardiovascular disease, diabetes and chronic inflammatory conditions such as asthma and rheumatoid arthritis.

Prolonged raised cortisol levels are thought to be responsible for these physiological changes (Wilkinson: 1996).

3.9 Gypsy and Traveller sites and environmental health concerns

Parry et al's (2007) study showed clear health differences between Gypsies and Travellers, dependent on their living situation. Data indicates that those living on local authority sites or in permanent housing are more likely to suffer from long term conditions than those living on smaller privately owned sites, or those who live on illegal encampments (54%, 45%, 39% and 30% respectively). The same pattern is found for the EQ-5D tariff scores. This may in part be the result of those who are in the worst health being forced to settle in order to obtain the treatment they need, but many authors and Travellers themselves associate better health with the 'travelling way of life' itself.

Beyond the mental health aspects of travelling, there appears to be a growing body of evidence to suggest that environmental health issues associated with local authority and private sites exert an influence on the physical health of travelling communities living there. Doyal et al (2002) and Parry et al (2004) have noted that every Gypsy respondent in their study made a link between their accommodation situation, site conditions and health. This would appear to be in line with the government's own studies such as the Black Report on Inequalities (see MacIntyre: 1997) and the NICE review on housing and public health (Taske *et al.*, 2005) which concluded that the greater the housing deprivation, the greater the probability of ill health and that those who have experienced housing deprivation in earlier life are more likely to experience ill health in later adulthood.

The elements of housing which can have an effect on health include:

Factors which relate to the quality of the internal environments such as indoor pollutants, hazardous structures, cold and damp and noise, [and] factors relating to external social environment such as quality of the neighbourhood and access to amenities, safety and social cohesion.
(Taske *et al.*, 2005)

Van Cleemput (2007a) interviewed many Traveller families who felt that their sites were “a health hazard” because they were situated close to motorways or rubbish tips and other undesirable locations where other communities did not want to live. Many respondents mentioned noxious smells, flies, and other hazards such as exposed power lines and barbed wire fencing, which they worried could cause accidents for their children and therefore restricted their children’s ability to play outdoors. This was the case on the Westway site in west London which is right next to a flyover and an industrial plant producing vast amounts of dust. Health visitors to this site noted high levels of asthma and eye infections in children and adults (Chelsea and Westminster PCT: 2005).

Niner (2002) found that many Traveller sites have amenity blocks which are unfit for purpose, due to vermin infestation, damp, lack of heating and poor building quality. Power (2005) raised concerns about overcrowding, especially in terms of shared washing, cooking and toilet facilities. Pitches were often found to be below standard and uneven, which could lead to accidents. Health visitors to the Westway site drew attention to the lack of foot paths which meant children were exposed to traffic accidents, gas cylinders which were not stored safely (and could therefore present a fire hazard) and the number of untethered dogs roaming the site who might bite residents and visitors as well as present a disease risk through their faeces (Chelsea and Westminster PCT: 2005).

3.10 Interventions

Whilst the body of existing literature is beginning to provide a clearer picture of the issues affecting the health of Gypsies and Travellers, many of the articles reviewed highlight the dearth of research into this area in terms of understanding exactly what can be done to address the inequalities between these communities and the settled population (Mariehems Health Centre: 2001).⁵ This is an important finding in itself which also further legitimises the need for this research project.

Nonetheless, this review has uncovered a number of interesting interventions which have been implemented. These are discussed in the next section under the following groupings:

- The response of National Governments;
- Community development;

⁵ This report in particular calls for a more evidence-based approach to looking into the health issues and experiences of Gypsies and Travellers.

- Health provider initiatives;
- Patient-held records;
- Monitoring of ethnicity; and
- Recommendations.

3.10.1 The response of National Governments (British, Scottish and Irish)

The differences between the approaches of the National Governments (including British, Scottish and Irish) to addressing the health inequalities of Gypsy and Traveller groups are notable.

The British Government's 2007 *Pacesetter's Programme*⁶ is regarded as an unusual development in its policy towards Gypsies and Travellers. The programme aims to reduce health inequalities in partnership with local communities, and specifically targeted Gypsies and Travellers. The programme involves the Department of Health working with five strategic health authorities on the programme to deliver equality and diversity improvements and innovations. However, the Pacesetters Programme cannot be regarded as a national programme to addressing the issues, rather it is dependent on individual PCTs taking the lead and disseminating good practice.

In Scotland, there has been a Secretary of State's Advisory Committee on Scotland's Travelling People since 1998. This has been responsible for developing a range of proposals on how to address health challenges that travelling people in Scotland face. However, there has been criticism that these proposals are worthless since they are not being backed up with adequate funding and Government momentum (Smart, Titterton and Clark: 2003).

A range of research and best practice around the issue of Gypsy and Traveller health has emanated from the Irish Government. In particular, the National Travellers' Health Strategy⁷ was launched in 2002 and is deemed to provide an effective framework for Travellers' Health by pressure groups (McCabe & Keyes: 2005). The strategy is based on the idea that "Travellers have a right to appropriate access to healthcare services, which takes into account their particular needs, culture and way of life". The Social Inclusion Unit (in the Department of Health and Children) supports the Traveller Health Advisory Committee and

⁶ www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/Pacesettersprogramme/index.htm

oversees the deployment of the Traveller Health Strategy. Furthermore, Traveller Health Units have been set up in each Health Service Executive region. ***A Report on the Activities of the Traveller Health Unit in the Eastern Region*** (Irish Health Services: 2004) discusses the need for and work of the unit. Initially focusing on recommendations for monitoring and evaluating health service provision for Travellers, the unit began to raise awareness within the health service about the importance of tackling Travellers' specific needs alongside building capacity within the travelling community to work with the health board (discussed in more detail below).

3.10.2 Community Development and the benefits of lay health workers

Building capacity within the community itself, in terms of participation, consultation and active involvement in interventions, has been suggested as an effective way to change behaviour and address health care access issues.

One project in particular, based on the idea of community development, is frequently mentioned in the literature reviewed as a source of best practice and has been replicated in other areas (for example in Tavares: 2001; and Greenfields: 2008).⁸ This project was piloted by the **Pavee Point Primary Health Care for Travellers'** programme in Dublin.⁹ The philosophy behind the project (and others Pavee Point have developed) derived from its definition of primary health care in communities as "enabling individuals and organisations to improve health through informed health care, self help and mutual aid" (McCabe and Keyes: 2005). Sixteen women from Gypsy and Traveller groups were trained to become Community Health Workers. Firstly, the project worked with these women to help identify their health needs and set up support and training around those needs, secondly, the Community Health Workers were used as peer educators in their communities.

Gypsies and Travellers in Leeds – Making a Difference discusses the importance of - and recommends - community development for readdressing the relationship between the inequalities of power and ill health, and in particular advocates the relocation of power away from health care professionals to members of the community (Tavares: 2001).

The authors of the ***A literature review of the health of Gypsy/Travellers families in Scotland and the challenges for health promotion*** conclude that genuine engagement and community development are important and effective means to improving problems with socially excluded communities. However, they stress that it can take time to build trust with

⁷ http://www.dohc.ie/issues/Traveller_health/

⁸ Replicated by Sussex Traveller Health Project

⁹ http://www.paveepoint.ie/progs_health.html

such groups, particularly when a group's or individual's experience of health professionals has been negative. Appropriate training of healthcare professionals is therefore recommended to ensure that their approach is culturally-sensitive and, furthermore, they state that health providers need to win internal staff trust in addition to the trust of community in which they are working. They caution that the impact of community development initiatives may take a long time to become apparent.

The report on the **Highland Gypsy/Traveller Health and Wellbeing Initiative** also emphasises the importance of community development in its approach to Gypsy and Traveller health (The Highland Council/NHS Highland: 2005). The range of actions that it undertook to address the five objectives that its steering group outlined were all underpinned by the idea "nothing about us without us".

Finally, there are two other projects that were identified that use the community development approach. The Ormiston Children and Families Trust via the Cambridge Traveller's Initiative developed a peer education drugs project, working with a group of Gypsy and Traveller women (Warrington & Peck: 2005). A community pilot project, 'Skills for Health', is being delivered in Thurrock (funded by DH and DFES), which seeks to teach mothers from Gypsy and Traveller communities basic health skills training (Warrington & Peck: 2005).

Awareness raising about drug abuse in Gypsy and Traveller communities: The Gypsy Media company produced a DVD in 200x funded by the Home Office National Drugs Strategy which aimed to raise awareness about drug abuse, and reduce the stigma and shame which prevented this issue from being discussed publically amongst Gypsies and Travellers. This DVD contains frank self portraits and advice from members of the community to each other about the perils of drug abuse and what impact it has on the community. The DVD was distributed with the Travellers Times newsletter to members of the community.

3.10.3 Health Provider initiatives

Several health providers have sought to improve access to local health services for Gypsies and Travellers:

- **Bristol Traveller Health project:** This project has involved a number of different initiatives including a mobile dental unit (Doyal et al: 2002). One of the most popular initiatives was a Well Woman service with monthly clinics for screening and health promotion as well as the treatment of chronic problems (it has now ceased due to lack of funding).

- Specialist health visitors: ***Gypsies and Travellers in Leeds - Making a Difference*** documents the attributes of the successful specialist health visitor approaches it reviewed. These attributes include: developing an understanding of cultural issues, developing a relationship of trust and respect with the community, extended support role of a health visitor, flexible and informal approach to offering advice, being flexible (for example providing alternative approaches to measuring pain - not in terms of days or weeks owing to the lack of cultural importance placed on time in Gypsy and Traveller communities), development of multi-agency partnership working and of a local health visitor network, and patient-held health records (Tavares:2001).
- On-site Primary Health Care: reported again in ***Gypsies and Travellers in Leeds - Making a Difference*** as being ‘most’ effective in helping these communities access health care (Tavares:2001).
- **A pilot project in Thurrock** has established a nurse-led Personal Medical Service (PMS), specifically targeting ‘homeless people, travelling families and asylum seekers’ (Warrington & Peck: 2005). Six hundred and fifty Gypsies and Travellers were currently registered at the centre and they used a combination of salaried GPs, drop-in sessions and telephone appointments to effectively increase the uptake of primary health care services among this group.
- **Ormiston Children & Families Trust in partnership with Cambridgeshire and Peterborough Mental health Partnership NHS Trust** is delivering an emotional wellbeing advocacy service and learning from this work will be evaluated and shared across the nation in the future (Warrington and Peck: 2005).
- **Westminster Primary Care Trust** monitored and assessed the health needs of the population of the Westway Travellers’ Site over a five-year period and has acted on their findings (Burchill, Flynn and Russell: 2005). Health promotion activities it undertook as a result include: oral health, sun safety, accident prevention, stress management, fire safety, access to health services, stop smoking and women’s health. Following a health assessment five years after this rolling promotional programme, improvements in health and access to health services were noted by the PCT. The PCT’s Health Team also worked with a multi-agency group to bid for refurbishment of amenities on the site. As a result, it is looking to continue more promotions based around health eating, physical activity and domestic violence awareness.
- **Cambridgeshire PCT** recently published a Traveller’s Health Strategy document (2007), based on numerous consultations with Gypsy and Traveller communities and

other stakeholder groups, supported by the Government Office for the East of England. The document sets out a Vision for improving Traveller health in the region and reducing health inequalities between Gypsy Travellers and other groups. Examples of best practice noted in the Strategy included: clear lines of communication and partnership working between local authorities and PCTs so that assessments are made before Gypsies and Travellers are moved on; incentivising GPs to register Gypsies and Travellers and not penalising them for missing practice targets; using a mobile Police van to provide medical services; providing a laminated card with the telephone numbers of health visitors and other contacts, such as NHS Direct, on it; providing information in DVD format; and developing information packs for new arrivals on entitlement to services and how to access them. Other ideas from the consultation included establishing a support network for health visitors to share information and spread best practice, proactive health checks on sites, the availability of same-gender GPs, chronic illness care through improved self-management (Expert Patient Programme) and increased use of mobile phone technology for appointment reminders and communications with HCPs.

- **Training for health care professionals dealing with Gypsy and Traveller communities:** Derbyshire Gypsy Liaison group have developed a 'how to guide' for professionals dealing with Gypsy and Traveller communities in a health care setting. This booklet, entitled "A better Road" was written in 2004 and has been updated in 2008. It includes an easy-read synopsis of the cultural heritage of Gypsy and Traveller groups, their current living situations and the legal context. It also describes in detail specific cultural issues which might cause problems in a health care setting and provides recommendations to health care professionals on how to deal sensitively with these issues
- **Insight into emotional health and wellbeing amongst Gypsy and Traveller communities:** In 2008, The Derbyshire Gypsy Liaison group in collaboration with the University of Central Lancashire and CSIP East Midlands produced a report entitled "I know when it's raining", which focuses on emotional health and wellbeing amongst Gypsy and Traveller communities. This was developed as part of the Delivering Race Equality action plan for mental health services community engagement programme between 2005 and 2008. The report provides statistical analysis of results from questionnaires administered within the local community and provides recommendations for dealing with mental health issues in the Gypsy and Traveller communities. It especially emphasises the issues faced by Travellers who go into 'bricks and mortar' housing.

3.10.4 Patient-held health records

Giving individuals their health records has been piloted in several areas as a way to overcome the issues around using multiple general practices or health care services due to mobility:

- The '**Parachute Team**' in **Peterborough** has developed a hand held record card for members of Gypsy and Traveller communities (Warrington and Peck: 2005).
- **The Canterbury and Traveller Support Group** are currently running a 27 month pilot programme in conjunction with Christchurch University, where members of Gypsy and Traveller groups are being given credit card with their NHS and health information.¹⁰
- **Hand-held records** (records that are held by patients themselves rather than by their GP), which have been piloted in Scotland as well as in maternity services within the UK, could be used by all PCTs rather than each PCT devising separate, costly duplicates (Matthews: 2008). The Secretary of State's Advisory Committee on Scotland's Travelling People recommended a system of Traveller-held records throughout Scotland back in 1999 and it is an intervention also recommended by The Ormiston Children and Families Trust, advocating the development of the system at a national level or at the very least a regional level to ensure continuity of service (Warrington and Peck:2005).

3.10.5 Monitoring of ethnicity

A common theme throughout the literature reviewed is the call for official routine demographic monitoring of Gypsies and Travellers. In its strategy towards developing a more effective evidence base the **Southwest Regional Observatory** calls for acknowledgement of Gypsies and Travellers as an ethnic minority (in practice as well as in legislation) and, secondly, routine monitoring of their ethnicity to ensure that health inequalities are more apparent and evidence-based (Doyal et al: 2002). These two steps accompany calls for more individual studies on particular groups of Travellers and Gypsies, systematic evaluations of local policy initiatives, as well as clearer accountability for monitoring and policy development and a financial and policy commitment from central Government to address health inequalities.

3.11 Recommendations

¹⁰ Information gathered by phone but see also <http://www.canterbury.ac.uk/projects/secc-project/Gypsy-Traveller-support%20group.asp>

This literature review has uncovered an array of recommendations which we have listed here for consideration and elaboration throughout the course of this research project:

- Inter-health authority coordination (Warrington & Peck: 2005).
- PCT partnership work with the local authorities to address sites in poor condition (Burchill, Flynn and Russell: 2005).
- A regional task force to coordinate strategies for reducing health inequalities experienced by Gypsies and Travellers.
- Liaison between local authorities and health authorities through health and social care partnerships, and including voluntary organisations, contingent on Gypsy and Traveller community buy-in (Van Cleemput and Parry: 2001).
- Group housing to enable members of Gypsy and Traveller communities to live together (Van Cleemput: 2007).
- Providing a day room for friends and family of Gypsy and Traveller patients at hospitals (Jesper et al: 2008).
- Development of peer education projects based on best practice models should be piloted, evaluated and rolled out (Warrington and Peck: 2005).
- Training for health service providers, especially front line staff to ensure they are able to address both internal and external racism (Warrington and Peck: 2005).
- Health promotion material, developed with Gypsy and Traveller communities, in an appropriate format (Warrington and Peck: 2005).

Stakeholder research

4. Stakeholder research

As we know from the review of literature on the health of Gypsy and Traveller communities, these communities are considered to be amongst the most disadvantaged groups in British society (if not the most). They are subject to significant health inequalities when compared to the rest of the UK population. Findings from the Stakeholder interviews suggest that the situation of Gypsies and Travellers is broadly similar in Mid Essex to the rest of the UK¹¹. Below we have outlined the main findings of the stakeholder research, in terms of specific health behaviours and how cultural beliefs and traditions impact on these behaviours and access to services, and the relationship between Gypsies and Travellers and healthcare professionals.

4.1 Lifestyle in Gypsy and Traveller communities

In this section we outline the stakeholders' key thoughts on Gypsy and Traveller behaviours in relation to specific aspects of health.

4.1.1 Diet

The Gypsy and Traveller diet is traditionally a high-fat diet based around traditional home cooked dishes, though there is some indication that fast and processed food is becoming more pervasive. This is coupled with a relatively poor knowledge of healthy eating, illustrated by the view of a Health Visitor below:

There's [a] definite lack of understanding of healthy living with some of the Travellers, and I suppose, that's also part of the fact that big is beautiful as well, especially in men, so the idea that a big man...has more status.

Although it is recognised that living conditions are generally improved from those of the past, there is some feeling that affluence can actually impact negatively on health. Having more disposable income can enable people to afford unhealthy junk foods, rather than relying on catching and picking more healthy food as poorer past generations would have done. This phenomena, along with what is considered to be a more less active lifestyle (with many Gypsies and Travellers now living a less itinerant lifestyle than traditionally because of restrictions on roadside/unauthorised stopping), is thought to be partly responsible for high rates of obesity and diabetes amongst Gypsy and Traveller communities. These are considered to be problems for men in particular, and, along with coronary heart disease, are

likely to be the most common health conditions, although there is uncertainty over whether incidence is any higher than in the general population (it is likely that outcomes are worse as there is a reluctance within the Gypsy and Traveller community to seek treatment for health conditions, discussed in detail below).

As suggested in the literature review, Health Visitors have found that there are strong beliefs around infant nutrition and weaning. A large, plump baby is seen as a healthy, well looked-after child and in addition it is also considered to be a sign of prosperity. There is some evidence that mothers believe they need to give extra vitamins to their child, even when it is not necessary, and breast feeding is rare because of the lack of privacy in caravans and men not wanting to witness it, which have implications for the health of Gypsy and Traveller children. This is discussed further in the section on the impact of culture on health behaviours below.

4.1.2 Smoking

Stakeholders highlighted, as did the literature review, that smoking within Gypsy and Traveller communities is endemic, with self-rolled cigarettes the predominantly chosen form. Smoking is usually taken up at a very young age – frequently around the age of 14 or 15, particularly among men. Smoking is, however, also common among women, and discouraging pregnant women from smoking during pregnancy can be challenging - healthy children born to a mother who has smoked throughout the pregnancy will often be used as evidence that it does not harm a child's health. This also reflects the importance of word of mouth and friends', families' and neighbours' views within small and quite enclosed communities, in the development of views and behaviours around health issues.

4.1.3 Alcohol consumption

Alcohol consumption is common, particularly among men and, as with smoking, is commonly taken up before the age of 16. It is felt that young women, however, are more likely to drink now than in the past, as a result of greater attendance at nightclubs and other social gatherings outside of the Gypsy or Traveller community. While alcohol abuse can be a problem, there is some suggestion that there can be a collective denial within a community about conditions such as alcoholism and that someone who actually suffers from alcoholism merely 'likes a drink'. This is linked to general attitudes towards dealing with health problems, dealt with further below.

¹¹ While all statements about the prevalence of health conditions and behaviours are anecdotal, these

4.1.4 Drug Use

As indicated by the literature review, it is commonly believed that drug use is more common amongst Gypsy and Traveller communities now than in the past, but not necessarily to any greater extent than in wider society in general. However, considering that accessing health services tends to be more difficult for travelling communities, there may be issues in getting treatment for those with drug problems. Prevention might also prove difficult as a result of Gypsies and Travellers leaving school before any drug-related education takes place. Since drug use is a taboo subject within the community, most stakeholders had had little experience of dealing with or discussing drug-use, and did not feel qualified to comment on this in detail.

4.2 Specific health issues in Gypsy and Traveller communities

4.2.1 Sexual health

Contraception is a sensitive subject within the Gypsy and Traveller communities. The most traditional groups, the Irish Travellers, are the least likely to use any contraception at all, though some of the stakeholders reported women accessing the contraceptive pill without the knowledge of their husbands. Contraception was felt to be more acceptable within the non-Irish Gypsy community, though the feeling was that condoms were almost never used, and that the contraceptive pill was the method of choice. This allowed women to have much more control over the size of their families and to have breaks in between pregnancies.

However, access to contraception and information about contraception was thought to be patchy, and depended on word-of-mouth within the community or through a GP or healthworker. Maintaining use of the contraceptive pill was reported to be difficult, as women have to make regular visits to their GP for prescriptions which might not be possible when travelling, and strict timekeeping is necessary, which was also thought to cause difficulties. Abortion was mentioned as something which probably happened within the Gypsy and Traveller community but which did not get discussed.

A local midwife reported that generally families were started young and strong Catholic beliefs, especially amongst Irish Travellers, tend to preclude the use of contraception, and abortion even in cases where the child is suffering from a serious health condition. Generally it is thought that these incidents are considered to be 'God's will'.

are common themes running through stakeholder interviews and areas believed to be important to follow up in subsequent research.

In terms of awareness, prevention and treatment of sexually transmitted illnesses, the stakeholders felt that this was not seen as relevant to the Gypsy and Traveller communities as members' only sexual experience was once married. However, it was also said to be the case that often Gypsy and Traveller men were encouraged to have sexual relationships with non-Gypsy/Traveller women before they married, which would suggest that the community was still at risk from sexually transmitted illnesses.

4.2.2 Antenatal care and pregnancy

A local midwife who regularly deals with Gypsy and Traveller women felt that generally women are fairly 'savvy' about the need for antenatal appointments and routine checks and scans. She feels that most Gypsy and Traveller women do attend for these in the local area, largely due to the fact that the local maternity hospital has an excellent reputation amongst this community. Although there may be some delay due to women travelling, this stakeholder felt that most Gypsy and Traveller women anticipate and plan for this so as not to miss any appointments. However, it is acknowledged that Gypsy and Traveller women generally do not attend antenatal classes or parenting sessions, preferring to deal with this within the family. In terms of the birthing process, this is often a very private affair with men generally waiting outside the delivery suite, and women preferring to return home as soon as possible after the birth.

4.2.3 Children's health and immunisations

For a variety of reasons, immunisations are thought to be used less among Gypsies and Travellers than the general population. Most of the stakeholders linked this to an inability to keep track of immunisations because of their travelling lifestyle (and changing GPs), though some pointed out that 'The Yellow Book' had attempted to mitigate this by providing a section on medical information which could be easily transported. Stakeholders felt that a portable medical record, which would be filled out by GPs, would help Gypsy and Traveller parents obtain their child's immunisations even better.

In addition, as with the general population, suspicion around the MMR jab had had an impact on take-up, and this has fed in to a wider suspicion of authority more generally:

They see authority as being there only to enforce against the Gypsy community, never provide for it. And so they were all deeply suspicious of why a health visitor might be telling them certain things.

The barrier of illiteracy seems to exacerbate the impact the media coverage on subjects such as immunisation (or other health-related matters) can have. For adult populations who cannot read, the television and radio are more relied upon sources of information, and Health Visitors have found them to be frequently quoted sources.

4.2.3 Mental health

Gypsies and Travellers are known to suffer disproportionately from mental health problems. Stakeholders cited the stress of evictions from unauthorised sites, poverty, and isolation for those living in houses.

[Housing a Traveller is] like taking a wild bird and putting it in a cage. So basically what happens is that you magnify the problems.

Mental health is a taboo subject in Gypsy and Traveller communities and is only discussed under euphemisms such as ‘worry’. This reluctance to discuss mental health has huge implications for the treatment of mental health problems in the Gypsy and Traveller community.

4.2.4 Cancer

Like the words ‘mental health’, the word ‘cancer’ is taboo in the Gypsy and Traveller community, and if it is discussed at all it is covered with euphemisms such as ‘the thing’. Cancer was perceived by the stakeholders to be a major health issue in the Gypsy and Traveller community – lifestyle factors make incidence high as in the general population. In addition, this reluctance to acknowledge cancer – there is a belief that discussing it is tempting fate – leads people to avoid screening, not recognise symptoms, and to not address symptoms once they become apparent. The tendency to only discover cancer in its later stages reinforces fatalistic views of cancer as a ‘death sentence’ which cannot be treated.

4.2.5 Environment

Gypsy and Traveller sites are often located in places not normally chosen as places to live, such as beneath electricity pylons and next to motorways, which often bring associated health impacts and safety risks. Furthermore, employment is commonly in industries such as scrap metal, landscape gardening and tree surgery, often using dangerous tools and requiring heavy vehicles, such as lorries, to be present on site. Combined with children running around on sites, accidents are relatively common.

However, a Local Authority officer stated, “no one site is the same as another”, and these factors impact differently from one type of site to another. Roadside sites suffer from magnified health and safety concerns and stress is often increased from the repeated threat of eviction. Furthermore, those living on the roadside are generally poorer – lacking the facilities found at permanent sites, such as electricity and running water. One community worker gave an example of a family having to go to the local McDonalds to plug in their nebuliser for their child who was suffering from an asthma attack. This lack of the basic amenities is often combined with an absence of official information about available services, further marginalising people from necessary health care.

4.3 Cultural beliefs and norms in Gypsy and Traveller communities

4.3.1 Gender-related health

Traditional gender roles are evident in Gypsy and Travelling communities: women predominantly look after the family and do not work outside the home, whereas men are very unlikely to take a ‘hands-on’ role in bringing up children and are the main sources of income for their families. This has many implications for women’s health (commonly women will have many children, with their first at age 16) as well as the way that gender determines access to healthcare services. It is often thought that women are more likely to access care more easily than men in Gypsy and Traveller communities.

Women, I think, in any community, are kind of the guardians, aren't they, of particularly their children's health, and are the people who will have contact with the health visitors and doctors.

However, women traditionally show a strong respect for men and elders’ views, frequently wishing to get the approval of their husband, brother or father before they act, which might prove a barrier to their accessing healthcare. Traditional views around privacy and respect also operate in these communities; it is thought that most Gypsies and Travellers are unlikely to discuss health-related issues in the presence of someone of the opposite gender. Health Visitors confirm that breastfeeding is rarely practiced given that there is often no private space, as this is something that men should not see. This also prevents attendance at antenatal classes, which means that often women do not get adequate antenatal care.

Irish Traveller communities are thought to have the most traditional gender roles; Irish Traveller women are more likely to follow the traditional path of bringing up a large family,

when compared to English Gypsies who can be from more liberal families “open to the idea of personal choice”.

Health issues specific to women are not openly discussed in Gypsy and Traveller communities. Stakeholders reported poor understanding of women’s health issues and basic human anatomy, as knowledge is not passed from one generation to the next. This has a major impact on women’s health as it results in a lack of understanding of menstruation and pregnancy, which can lead to both physical and mental health issues. Stakeholders reported Gypsy and Traveller women saying that they thought that they were ‘bleeding to death’ when they had their period for the first time; likewise, there were reports of women who did not understand that they were in labour, or what giving birth would involve.

They’re reluctant to talk about bodily functions, or anything to do with the body. Most girls are not told anything about puberty.

For delivering messages on these subjects, members outside of the community were considered by the stakeholders to be more appropriate, partly because of the lack of knowledge within the community on these subjects but also because of social barriers preventing these subjects being discussed within the community.

Reaching girls at the right age is difficult – they don’t go to school, they don’t talk about personal issues within the family or community. Education might happen face-to-face but it would have to be from someone outside the community, one-on-one and would have to get the permission of the mother.

For men, while discussion of health issues is limited, it is even less likely to take place if it concerns matters of personal health.

I can’t even imagine situations where you’d get Gypsy men talking about testicular cancer and self examination, without it turning into a joke.

One Health Visitor claimed that they had seen evidence of domestic violence, and this has been reported as an issue elsewhere in the literature, but that women suffering from it would very rarely use available public services because it would be considered to be private and best dealt with in the community.

4.3.2 Death

One example of Gypsy and Traveller culture which has been particularly difficult for health service providers to understand is that the extended family should be present when a family

member dies to touch the body and 'help them pass over'. Hospitals do not always recognise these needs and find it difficult to accept large groups of people visiting at one time. This is thought to prevent people from seeking hospital treatment and receiving the palliative care which makes people's final days more comfortable. However, stakeholders thought that attending in large numbers is not as much of an issue as it used to be and that the message is gradually getting through – both to Gypsy and Traveller families who arrive at the hospital in smaller numbers and the hospitals who are becoming more accommodating of family attendance in large numbers.

4.4 Barriers to accessing health services

In addition to the specific health-related behaviours which have been discussed above, the stakeholders also discussed a number of ideas which exist within the Gypsy and Travelling communities which have an impact on access to health services in general.

4.4.1 Independence

As highlighted in the literature review, Gypsy and Traveller communities retain a strong desire for independence and self-reliance for their community. This can lead to a reluctance to access health services unless absolutely necessary, which can in turn mean waiting until a health condition is at an advanced stage before seeking treatment. This probably means accessing hospital Accident and Emergency Departments rather than a GP, and makes the treatment of the condition much more difficult than it would have been had it been diagnosed in its early stages.

The high value placed upon independence, stoicism and self-reliance (particularly in men), which was discussed in the literature review, was reiterated by stakeholders, and it is thought that women are generally more likely to access services than men because of this.

There are a lot of men, in particular, who will not access health services because it's seen as a sign of weakness to admit any kind of frailty or problem.

4.4.2 Trust and familiarity

Trust is frequently viewed as being the single most important factor for healthcare professionals trying to reach Gypsies and Travellers. People from The Gypsy and Traveller communities can be quite selective with the GP they register with and will normally rely on recommendations from friends and family and whether the GP is known as being

understanding and patient. Likewise, one negative experience, such as problems with getting or attending an appointment, could prevent use of that service again.

It was suggested that the difficulty in registering with a GP compared to simply showing up at hospital Accident and Emergency led Gypsies and Travellers to use the latter as their first port of call for medical attention. In addition, the stakeholders felt that Gypsies and Travellers tended to return to a trusted source, so if they had been to Accident and Emergency once they were likely to go again rather than to register with a GP. One example was given of a Gypsy family taking an ill baby all the way to Leeds to see a GP as they had been refused access to a GP's surgery in Essex.

This highlights a lack of knowledge of other local services, but also a desire to use familiar services where experiences have been more favourable and trust has already been developed. Similarly, familiar services might be accessed – the example given of a mother going to the same hospital as her baby was born in for an emergency, even though it has no Accident and Emergency department.

Continuity of service is something expected by Gypsy and Traveller communities as this is where trusting relationships can be developed. For example, many expectant mothers will expect the midwife to be present at the birth of their child (which causes distress when this doesn't happen) and do not like meeting new people when they are going through what is a very personal experience.

This continuity of service can be a particular challenge for less regular or more impromptu services where staff do not have the opportunity to build this relationship with their patients. Training of ambulance crews – such as making visits to Gypsy and Traveller sites to help familiarise patient and health professional with each other - is felt to be particularly useful in combating this.

4.4.3 Education and information

Although school attendance is thought to be better than has been the case in the past (and probably better even than five years ago), children below the age of 16 can and often are removed from school. Parents believe there to be many harmful effects on their children, particularly female children, attending school, such as access to smoking, alcohol and sex education. There might be a preference for single sex schools to keep the girls 'pure' for marriage and avoid mixing with boys. If this cannot be accommodated (and often regardless of whether it can be accommodated), girls will often be removed from school once they reach puberty.

Where children are removed from school there is a concern that they are prevented from accessing traditional health messages promoted within schools such as the 5-a-day initiative and organised, scheduled exercise. Furthermore, it is thought that Gypsy and Traveller children are less likely to take part in activities which they might otherwise do outside of school hours, such as sporting events, contributing to a less active lifestyle.

Due to historically poor school attendance within the Gypsy and Traveller community, literacy is very low in the adult population, although it is generally better among the young. The low level of literacy in the Gypsy and Traveller community has huge implications for the communication of health services and the Gypsy and Traveller population's access to them. This is something which came up in the literature review and something that we were aware of at the start of this research – indeed, one of the aims of this research is to find ways in which the Mid Essex Gypsy and Traveller community can be informed about – and supported in accessing - health services in the future.

A possible link to this absence of education is superstition which remains important for Gypsies and Travellers and can lead to a reluctance to discuss health problems (as described on mental health and cancer specifically above) as this is seen as bringing bad luck. Health myths can therefore still exist, for example that epidurals will cause long-term paralysis. How to combat these myths and to provide healthcare in the face of such superstition, balanced with a respect for the cultural beliefs of the Gypsy and Traveller community is another key question for this research.

4.4.4 Health care professionals and their relationship with Gypsy and Traveller patients

There is general agreement among Stakeholders that Gypsy and Traveller communities are generally willing to engage with health services, although often they may be nervous about doing so or not have access to the information they need to do so. In addition, it was felt that women are more willing to access services than men. As we discussed above, trust was considered to be key for building relationships between the Gypsy and Traveller community and local healthcare providers.

The Stakeholder interviews revealed the importance of 'point of first contact' with services, that the receptionist in any health service should not be underestimated, as a patient must communicate with them if they are to get access to a healthcare professional. If Gypsies and Travellers do not understand the procedures they must go through or believe that they have suffered from any form of discrimination this can colour their whole experience of accessing care. Discrimination is a key issue for Gypsy and Traveller communities – their isolation from

the general population and direct experience of discrimination has engendered a fear of accessing health services, and staff who hold 'point of first contact' positions within the healthcare system should be trained to deal with the individual needs of minority ethnic groups, including Gypsies and Travellers.

In this context, registering an individual to a GP's practice on a temporary basis can have important impacts on patient care. Previous patient records may not be available and there is a feeling that GPs do not feel as professionally responsible for that individual as they would for a permanent patient. Furthermore, an alert system is not activated within the computer system of the GP's practice as it does not know the patients' history, and medical advice is therefore not as tailored as it could be. This is a particular issue when it comes to screening rounds for, for example, cervical and breast cancer, or for Vascular Risk Assessment. Temporary individuals are also not part of the target system which GP payments are based on, further marginalising them from the system (as described in the literature review).

The mobile nature of Gypsies and Travellers can result in inconsistent care, using multiple GPs in relatively short periods of time. Furthermore, as Health Visitors are assigned to a GP practice, and will visit the children younger than five years old registered to that practice, if the inhabitants of a site are registered to five different practices, they will be receiving visits from five different Health Visitors. It is felt this can cause unnecessary overlap and potential lack of consistency in care. In the most extreme cases, it has not been unknown for individuals being prescribed multiple different drugs for the same condition. This is a particular issue as a result of the literacy problems within the Gypsy and Traveller community as described earlier. Health visitors reported seeing people with carrier bags full of medication but not knowing how to use it. Further confusion can occur if the same drug is different in appearance from one area to another. In this instance, Health Visitors are invaluable in providing follow up care and 'plugging gaps' in patient knowledge.

Flexibility is considered to be a key requirement of Health Visitors. Providing other types of support, such as filling in forms, even if not health related, helps build rapport and trust and allows other relevant information to be obtained about them. It is stressed however, that it takes time to build this level of trust. Having a private space on site was thought by some to be very useful as it provides a place where conversations can be confidential (for example about sexual health or domestic violence), which is often impossible in normal site situations. (However, some stakeholders felt that whilst these services have tangible benefits, they also provide no incentive for Gypsies and Travellers to access services off-site, therefore increasing their isolation as a community. While it could be argued this is no different for the wider population, it is perhaps more likely that Gypsies or Travellers could become over-

reliant on them due to their unwillingness or inability to access other health services in the traditional way. This will be discussed further in the next chapter.)

While privacy is important within these communities, boundaries of what is acceptable to discuss are often more relaxed between a Gypsy/Traveller and someone from outside the community than within the community. In this sense, certain messages may be more successfully delivered from healthcare professionals external to the community rather than peer individuals.

4.5 Interventions

4.5.1 Mobile versus static services

A strong theme coming out of the stakeholder interviews was that services do not necessarily need to be tailored towards Gypsy and Traveller communities, as the services which already exist are good services. The focus should instead be on enabling Gypsy and Traveller access to current services.

One concern around providing mobile services directly to Gypsy and Traveller sites is that it could leave people without the necessary skills of access once these services are removed, and risk leaving Gypsies and Travellers dependant on them. To illustrate this concern, one Health Visitor used the example of an individual she came into contact with who no longer took their medication for high blood pressure because the previous Health Visitor who used to help her did not visit the site anymore.

A further fear is that specific services might not be as good as services provided for the general population which could encourage alienation and also encourage separation from the wider community:

The council and a few agencies thought it was a good idea to turn the old warden's office into something that could provide services. But the community's against it because...why should we be treated on site, nobody else is treated on site and it keeps us in our little prison, so to speak...We shouldn't have to have alternative services. We should be able to access what's there.

However, there was some acceptance amongst the stakeholders that in certain circumstances, where needs were different for the Gypsy and Traveller community, that services be tailored specifically for the group. An example of this might be providing specialised antenatal classes, since attendance at mixed-gender classes caused a great deal

of embarrassment for Gypsy and Traveller people, or providing extra help and advice to pregnant women who perhaps did not receive education about women's health in school.

Another common view amongst stakeholders was that, whether mobile or static, services need to be offered by the same people over time to allow rapport and trust to be built between patient and provider. A particular challenge for this to be achieved is the regular turnover of staff, particularly Health Visitors. The idea of Community Health Trainers is one which has gained traction and it is hoped that the provision of these will help the Gypsy and Traveller community in Mid Essex to access all of the services which are available to them. However, it will be important to remember the notions of independence and privacy discussed earlier – the Gypsy and Traveller community appear reluctant to be monitored, and without building trust regarding how their personal information might be used it might be difficult to recruit people to take part in health programmes.

4.5.2 Information provision

The use of key individuals who are experienced in working with Gypsy and Traveller communities was highlighted as one area where knowledge could be transferred to other health professionals.

Practitioners that have got...specialist knowledge of Traveller communities...shouldn't just be used exclusively with Traveller communities. They should be used to make the service more appropriate for the community by passing on their [specialist knowledge] to other practitioners.

Moreover, it is felt that there is no substitute for these individuals, such as community development workers, as publications can get lost or become out of date and are often not appropriate for the Gypsy and Traveller audience. Delivering important messages face-to-face is generally thought to be the most effective method of communication with the Gypsy and Traveller community. NHS Direct is considered to be useful for providing general information such as locations of health services or which are most appropriate to attend for particular conditions, though evidence that the Gypsy and Traveller community is aware of and/or uses the service is sparse, and for more specific health questions, on the other hand, stakeholders considered it less helpful due to a likely lack of trust. The NHS choices website is deemed to be inappropriate due to the lack of internet access on the majority of sites (though according to some stakeholders this is changing and many young people now have regular internet access), low levels of literacy and the use of technical language on the website.

Peer education is generally thought to be a good idea when working with 'hard-to-reach' groups, and for the stakeholders was considered to be a good way of communicating health messages. However, it is important that health messages are communicated effectively (much bad information is passed around peers and reinforced by passing between peers and generations) and consideration should be given to the barriers that sometimes exist between people from within Gypsy and Traveller communities openly talking to each other about health issues and what messages or subjects they would feel able to broach.

One community worker stressed that racism and/or discrimination, as mentioned in the previous section, are not necessarily overt – services might be available but service providers need to ensure that communities know that they are there. This is a particular problem because Gypsy and Traveller communities are isolated in terms of their access to information.

It is important to acknowledge that there is also a need for sufficient and appropriate information to be provided for health professionals, as well as to the Gypsy and Traveller communities themselves. Ambulance services report that even the simplest training of frontline staff can help break down barriers and preconceptions about Gypsy and Traveller communities, increasing familiarity and cultural awareness. Training such as diversity awareness and visits by ambulance crews to Gypsy and Traveller sites is thought to have been successful and improved relations and communication between these communities and frontline staff.

4.5.3 Recent interventions

Parent-held child record books completed by the health professional when making visits have proved popular with Gypsy and Traveller mothers in the past. Take-up has been widespread on particular sites (Braintree) and they provide an accurate assessment of the child's health needs where they might not otherwise exist. However, this has not been universal and similar initiatives have failed elsewhere in GP surgeries (Writtle). In this case, there was a tendency for mothers to forget the cards and GPs do not always want more forms to fill in.

One possible solution was thought to be print-out sheets generated from the GPs visit record to then put in a parent folder. This would have the benefit of not requiring any extra work on behalf of the GP. They would be less visual, however, than anything specifically produced for this purpose (to combat illiteracy). It is recognised that social desirability can be an important factor within Gypsy and Traveller communities and that people will generally want to fit in with their neighbours. This is likely to be key to the success of uptake of initiatives such as this.

Delivery of opportunistic treatment in Braintree, whereby a GP would be assigned once a month and visit the site, increased uptake of immunisations greatly. This allowed health professionals to challenge some of the views and fears people have about immunisations such as the MMR vaccination. This also entailed giving prescriptions and helped reduce attendance at Accident and Emergency departments. A service such as this could also be suitable for prevention services such as smoking cessation. These services could be better utilised if taken into the communities and would bypass the problem of Gypsies and Travellers accessing services only when there is an emergency need.

There was some feeling that, although women are more likely than men to access services, children's services are not used as much as they could be. The development of a Travellers' group within the Braintree children's centre did not work and, although the exact reason for this was not known, there was a feeling that it could be because mothers did not want to be treated differently, or receive special treatment.

Further specific initiatives cited as providing useful case studies or possible outlets of information were:

- The Cambridgeshire Travellers Health Trust's work to improve access to services;
- A welcome pack produced by Fenland District Council for Gypsies and Travellers new to the area, covering information about local services; and
- The Savvy Chavvy website – a social networking website for young Gypsies and Travellers.

4.6 Outcomes of the stakeholder research

Some of the key themes which emerged from Stakeholder interviews in terms of what outcomes they wanted from the research included:

- Advice on family planning, women's and men's health checks;
- Greater engagement from adult males in health services;
- User-friendly services, and GPs that are sympathetic;
- More work on health promotion; and
- More open services, more respect for Travellers and more recognition of Traveller's needs.

Fieldwork with Gypsies and Travellers in Mid Essex

5. Fieldwork with Gypsies and Travellers in Mid Essex

In this chapter we describe the findings of the depth interviews carried out with Gypsies and Travellers in Mid Essex. There are a number of social, cultural and structural factors influencing health outcomes for Gypsies and Travellers in Mid Essex, which will be outlined in the first section of this chapter. Then we will go on to describe specific attitudes and behaviour around lifestyle, health issues specifically related to women, access to and use of healthcare and access to information about healthcare.

5.1 Social, cultural and structural factors influencing health outcomes for Gypsies and Travellers in Mid Essex

To understand the issues around health-related attitudes and behaviours of Gypsies and Travellers in Mid Essex there are a number of underlying social, cultural and structural factors which should first be addressed. Below we will discuss the impact on health behaviours of:

- Traditional gender roles
- The importance of family
- Fatalism
- The importance of hearsay
- Relationships with the settled community
- The decline of the traditional lifestyle and the context of Mid Essex
- Literacy
- The impact of the environment on health

5.1.1 Traditional gender roles

Gender-related cultural norms are extremely important in the Gypsy and Travelling community, and roles remain traditional, though how traditional seems to vary between families.

Women are the care-givers, do not work outside the home and spend most (if not all) of their time in the home. They tend to leave school before the age of 13 because their parents are concerned about the inappropriate behaviour their teenage daughters could be exposed to in mainstream schools (they disapprove, for example, of pre-marital relationships and sex). Gypsy and Traveller women tend to have poor literacy skills. A lack of empowerment can mean that women struggle to access services for themselves and their children, and might not do so unless their situation becomes very serious.

During this research we observed a number of instances where it was considered inappropriate for women to be outdoors and off-site; in one case a father told his adult daughter to “get back in the caravan”. Access to transportation (and therefore access to services) is also a problem for the women we spoke with - many did not drive or did not have the use of a car, were far from a bus route, and walking was often not an option due to the remoteness of the site and local roads being unsuitable or dangerous to walk on. In this sense, Gypsy and Traveller women can be trapped and isolated, which not only hinders their access to the wider community but leads to a less active lifestyle.

Men are brought up to be proud breadwinners and lead much of their lives off-site. There is a belief amongst Gypsy and Traveller men that they should be stoical and independent, and avoid grumbling, which seems to be particularly true of older members of the community. Time pressures are a problem for men in the Gypsy and Traveller communities - one woman we spoke with explained that her husband works six days a week from early in the day and does not get home until 10 o'clock at night. This makes men unable to access healthcare services, and means that conditions are often left to reach crisis point. Like women, Gypsy and Traveller men tend to leave school without any qualifications and literacy is an issue. This, combined with beliefs about appropriate topics of conversation, affect men's willingness and ability to access services, and mental health and sexual health in particular are taboo subjects.

It is crucial to understand the impact of these traditional gender roles on attitudes to health, health related behaviour and access to services, as will be shown throughout this report.

5.1.2 The importance of family

In addition to beliefs about appropriate behaviour for each gender, the Gypsy and Traveller communities we spoke with during this research place high value on the family and the ability of each member of the family to look after others. When caring for the elderly or disabled is discussed, for example, the feeling is that the appropriate forum for dealing with such matters

was the extended family, and they do not see the need for - or the appropriateness of - outsiders assisting with care.

She's had care offered to her but she likes to do it on her own, like just me and her... We like to keep it in the family. We don't like to depend on other people.
(Male, aged 30+, housed)

It is also clear that this is not simply a case of making do where medical or social care and benefits assistance is difficult to access, but an active choice on the part of families and individuals to refuse outside intervention.

The travelling community prefer to be with relatives, because we're always there if they need us, all they have to do is ring us and we'll be there. We look after us own family and it's the only way to cope really.
(Female, aged 50, Local Authority site)

[My parents] they're getting on now but they wouldn't want to go into a home. They wouldn't like that. No, they're too independent. No, no, they don't want to be looked after, and we can look after ourselves. [My mum says] when my time's up my time's up, I'm not going, I'm not dying in no hospitals and I'm not going to no homes. I'll die here.
(Female, aged 50, Local Authority site)

This desire for independence from the 'outside' community provides an additional layer of cultural norms which need to be acknowledged when considering options for improving service provision to Gypsies and Travellers.

Peggy, 46, English Gypsy, Local Authority site

Peggy lives with her husband in a tiny caravan. Since her boys have grown, they bought another small one so they can have their privacy.

Peggy feels ok today, but she does have high blood pressure, high cholesterol and asthma. Last year she couldn't get out of bed, couldn't catch her breath, and didn't know what was wrong. Thankfully her GP did some blood tests and found her some pills that worked. She had to try a few different ones though, the first ones made her swell up. Now Peggy takes extra care when she gets the prescription from the chemist that they are the right colour and brand name.

Peggy likes the fact that she's got her family on site, she just found out that her daughter in law is pregnant and is really happy for her. The girls usually come to Peggy for advice when it comes to their kids, as they know she's seen it all before. They make sure they check what to ask for at the doctors, and what Peggy thinks the problem is before they go down to the surgery.

Peggy does worry about her husband, she wishes he would follow the women's example and see a GP more regularly, like the time when he cut his leg open. That really needed stitches, but he wouldn't have it so she just patched him up as best she could. Peggy tries to keep everyone happy and well fed and the boys going to school. She wishes the young ones were a bit more interested in her pheasant stew and the helpful plant remedies she learned from her grandmother. Maybe the girls will think about it when they get older.

5.1.3 Fatalism

The Gypsies and Travellers we spoke with describe health not as an absence of disease but the ability to be active, work and/or go about their normal daily life. It was apparent that whilst many of the participants were in poor health, suffering from long term health conditions and caring for people with long term health conditions, such as diabetes, arthritis, high blood pressure, sleep apnoea, insomnia, heart disease, asthma, cancer and mental ill health such as anxiety and depression, they did not consider them or the people around them to be in poor health.

Is health a concern? Well not really I'm all right at the moment, bit concerning when you have a heart attack now and again.

(Male, aged 70+, Local Authority site)

Most of the people we spoke with seem to accept ill health as a natural consequence of ageing or as something that happens to everyone, rather than an unwelcome exception to the rule of a normal healthy life. This is perhaps in part due to the high prevalence of long term illnesses such as cancer, diabetes and heart conditions in Gypsy and Traveller communities, as well as environmental effects such as accident rates for children and manual workers.

Everyone knows someone who has had a heart attack or cancer.

(Couple, aged 40, Local Authority site)

There is evidence of fatalism amongst the participants in the research – whilst some participants discuss preventative health measures, most seem to feel that you would become ill regardless of these measures if it was ‘in the family’ or simply ‘if it was going to happen’. All of the participants in the research were able to recount a history of various medical problems in their family, and appear to accept that the same was likely to happen to them too in the long term. This demonstrated a belief in heredity as the main cause of illness and disease.

My brother died at 49 year old... he come home from work one day and he dropped dead of a heart attack. So it's like my mum's brother died of a heart attack, my dad died two years ago with a heart attack, it makes you think doesn't it?

(Male, aged 40, Private Site)

Well I might get run over by a trolley bus or have a heart attack, and it's a shame to go through that stress [of going to the dentist] isn't it, when you're going to drop dead anyway the next day?

(Male, aged 60+, Local Authority site)

In addition, religious beliefs seem to have a role in the fatalism of the individuals we spoke with, many of whom believe that illness and disease is 'god's will'. This is particularly the case for Irish Travellers.

5.1.4 The importance of hearsay

It is not surprising that the insular, family-focused Gypsy and Travelling communities, where illiteracy is high, rely a great deal of hearsay and stories circulating within the community for information. In terms of health, gossip and accounts from other family members who had bad experiences in hospitals or incidents of misdiagnosis by health professionals served to fuel a base level of mistrust in the health service. It is clear that messages from outside of the Gypsy and Traveller communities were overridden by those within it – an example of this is apparent in attitudes towards smoking during pregnancy, where women have seen others do so and still had healthy children, despite the messages that smoking during pregnancy is 'bad'. There is a preference for 'home remedies' amongst some of the older members of the Gypsy and Traveller communities. In addition, there are number of myths circulating around immunisations and their connection with autism.

Because we're so scared. You hear stories, oh it might be one out there, one in a million, but when you hear stuff like that, you do keep that in the back of your mind because it may be your kids.

(Female, aged 40, Private Site)

I don't really know how I feel about [immunisations]. I was worried, because didn't somebody come out and say it causes autism? I never give it to him. And he hasn't had it yet. And he's three in June. I thought if I give it to him and then he was autistic, I'd blame myself.

(Female, aged 26, private site)

Now, to be honest, I don't believe in no jabs, because I believe they're putting a germ into your body, and my belief is that if they get it their antibodies would fight it off. It's no different than putting a germ in them because their antibodies have got to get it and fight it off. So I had a, no, no, I've never had a jab.

(Female, aged 34, Housed)

Other misconceptions about health include a lack of recognition that they were not putting their health at risk through particular behaviours such as drinking.

It's not drink that [exacerbates my gout] so much, it's eating offal, you know organ meat parts, livers? They cause uric acid, and that's your kidneys playing up, it's supposed to send the uric acid into the bladder, and it sends it back in the blood stream, it turns to grit and seeps down to the lowest bones.

(Male, aged 60+, Local Authority site)

I've drunk near all my life. I've drunk enough beer to float a ship. But the right beer don't hurt you mate.... If you drink like dark beer, like very mild that don't hurt you mate. But too much bitter will mess your lungs up, like lager and all that, it's all chemicals. That'll kill you, mate...

(Male, aged 60+, private site)

A number stories circulating within the communities led to a distrust of health services. For example, some related participants referred to a case of a child in their extended family who had died in hospital in Ireland.

She was four. And there this doctor's telling her she'll be coming out, she was OK, she was getting better every day. You imagine us, everyday you're thinking she's going to come out, all of a sudden, she fell asleep and never woken up. So basically this is why you can't believe everything the doctor says to you.

(Female, aged 24, Local Authority site)

Whilst many health-related attitudes with their origins in 'hearsay' are present in the general population, it seems that poor literacy, access to objective health information and a mistrust of evidence given by outsiders need to be overcome in order to encourage as many Gypsies and Travellers as possible to use the healthcare which is available effectively. To provide effective healthcare to Gypsy and Traveller communities it will be necessary to challenge some of the myths around healthcare currently circulating and to find ways to encourage the spread of more positive messages.

5.1.5 Relationships with the 'settled' community

A layer of social interaction which may compromise engagement with health services is the closed nature of Gypsy and Traveller communities and the conflict which sometimes occurs with the 'settled' general population. In a closed community, stories about problems with outsiders spread easily, with limited contact with outsiders to challenge their accuracy (the same dynamic to that described in the section on 'hearsay' above). Discrimination was generally present in the collective experience of the families we spoke to, making many individuals wary of engaging with people outside their own community.

I'm registered to the one inside the town, it's nice, don't get me wrong, but they can be difficult when they want to be difficult with you. And sometimes I've think it's because we're Travellers.

(Female, aged 24, Local Authority site)

A few year ago I was in hospital with my brother. He never got as much attention as what the other bloke did next to him. But the bloke next bed to him he had it all, my brother felt he was treated a little bit different than he was because he was a Gypsy.
(Male, aged 50+, Local Authority site)

In terms of healthcare, where families have lived on the same site for many years and were settled with their own GP, mistrust of 'outsiders' is less of an issue. However, it can be a concern when dealing with unfamiliar people such as new receptionists, or hospital staff with whom they have not had previous contact.

Fear of discrimination can affect young people, where concerns about bullying at senior school in an unfamiliar town often leads to children being withdrawn from school, enhancing their isolation and negatively affecting their education.

My granddaughter doesn't go to school she's home tutored, I don't like her going to the big school, she had problems at the big school. Horrible in there they are, they pick on us.

(Female, aged 50+, Local Authority site)

Whilst the relationships between Gypsies and Travellers and the 'settled' population and public in Mid Essex appear to be better than those experienced in other areas of the UK, it seems that to provide effective healthcare to Gypsy and Travelling communities, trusting relationships between NHS Mid Essex and those communities should be maintained and strengthened.

5.1.6 The decline of the traditional lifestyle and the context of Mid Essex

The fieldwork reveals that there is a generational divide within Gypsy and Traveller communities in terms of accommodation preferences. Amongst younger Gypsies and Travellers there seems to be more willingness to move into houses, perhaps as they have not become accustomed to a travelling lifestyle since their parents settled when they were young. In addition, there seems to be more integration with 'outsiders' than there had been in the past and a greater push towards becoming 'settled', either on sites or in houses. This is perhaps a result of changes in the law which have made it more difficult to travel, and the desire for children to get a complete education. Amongst older people, however, whilst they might not travel frequently there is still reluctance to live in houses.

We are proper gypsies we are, we can't live in houses like because that's the way we are, we enjoy the outdoor life. We did try a house, we couldn't live in it, so we had to move and come on here.

(Male, aged 40, private site)

Some of those who lived in houses did so for convenience, health reasons or because they felt that it was better for their children's education.

In a house it's nice, you've got the convenience of running water, you can flush the toilet, bathroom, washing machine, dishwashers, tumble driers. If I had to live on a site I'd rather be in a house.

(Female, aged 35, housed)

Some had tried living in houses and had found it difficult to get used to as they felt trapped – this led some to move back onto sites, though some said that they had got used to it.

Yeah, when I first moved in it I felt like I was shut in, like I couldn't ... really just felt that the door ... and it was sort of, oh, the door's shut, I don't know no-one. I was like all boxed in.

(Female, aged 34, housed)

Some of the older Gypsies and Travellers we spoke with lament the decline of the traditional lifestyle – for many reasons this has been unavoidable, a result of changes in the economy which make travelling for seasonal work no longer viable and the law regarding encampments. However, some feel that intermarrying between Gypsies and Travellers and the 'settled' population and the trappings of modern life are to blame for a decline in the Gypsy and Traveller culture and feel that traditional attitudes and ways of life should be protected.

In Mid Essex, those who live on sites mostly do so semi-permanently, if not permanently, and therefore the effects of a travelling lifestyle on health and access to services is not really relevant to them. (The travelling population which spends time in Mid Essex seems to be very small.) It seems that this settling is at least partly because of the provision and management of land for Gypsy and Traveller pitches in Mid Essex. Most of the people we spoke with had lived in the same place for a long time, were registered with their GP and were aware of how to access health services in the area. It is important to recognise that, whilst exacerbated because of particular aspects of Gypsy and Traveller life, many of the health-related problems we discuss in the report are problems which are linked with lower socioeconomic groups and poverty in general.

5.1.7 Literacy

Because of the limited education many Gypsies and Travellers receive, poor literacy is a real issue for the Gypsy and Traveller communities and creates numerous barriers in terms of access to information and engaging with public services, including benefits and health services. Many experience difficulty filling in forms and are often embarrassed to ask for help.

5.1.8 The impact of the environment on health

The living situation of Gypsies and Travellers in Mid Essex was highly variable, even within sites. Whilst local authority sites tended to be well-managed and provided or facilitated access to necessary facilities (such as mobile blood pressure testing vans and mobile libraries), some felt that they lacked privacy and that people had no control over their neighbours, which caused a great deal of anxiety for some.

We had a nasty lot on here before. They're not a nice lot at all. That's the trouble with sites isn't it? Don't know who you're going to get next door to you when you live here. If you go on caravan sites if there's a lot of one family they'll bully everyone else, or get them out, you know?

(Female, aged 50, Local Authority site)

Many of those we spoke with feel that private sites are better designed, provided more appropriate use of space, and a certain amount of control was possible in terms of who lived on them. On the other hand, some private sites had less access to services which are provided by the site manager on local authority sites, and facilities which would be beneficial to their health and safety, such as pavements on the roads leading up to sites. In addition, the welfare of children is a particular concern, as sites can be dangerous and there is nowhere safe for them to play.

The oldest one, he was two he got hit with a car, he was playing out, and a little boy went in and put the handbrake down, and the van went on his hands.

(Female, aged 34, private site)

It was also felt that caravans were not safe environments to care for the elderly or disabled. The cold was felt to have a big impact on people's health in winter, especially where people have to go outside to use the toilet. In addition, lack of running water inside caravans makes day-to-day living hard work and necessitates being outside in poor weather conditions.

Just had enough of this life, running in and out for water, toilets. It was too much.

(Female, aged 34, housed)

Yeah, because my mum's caravan is really, really damp and she's waiting for a house. My mum's caravan is really, really damp and he [son with Down's Syndrome] got really chesty and stuff.

(Couple, aged 30+, housed)

Some of the people we interviewed feel that rats are a problem on sites (possibly due to where they are located) and a number claim that the dogs on sites often bite children, as well as scaring away health-visitors and other public services (such as the postman) who would otherwise come onto sites.

Mid Essex is a largely rural area, and during the research we saw many small sites (generally private sites) which were many miles away from other communities. Access to sites seems to be poor, because of remoteness, lack of public transport and/or dangerous roads with no pavements. This makes it difficult for people to get on and off, and prevents access to public services such as GPs, hospitals and schools, other amenities such as shops and entertainment and makes emergencies very difficult to deal with. This is a particular concern in terms of the contribution it makes to trapping women (without access to vehicles) on sites and making it difficult for them to access the services they might need for their families.

When they want to go to the big school there they can't walk up there because you're not allowed to walk on this side of the road. And you can't push a pushchair, there's no pathway up there, it's not a thing what you walk, it's a motorway. It's dead dangerous. And I'd like to walk to the shop, but there's been loads of accidents on that road, if the police do catch us they just send us back. It's too dangerous anyway even if they didn't send us back.

(Female, aged 50, housed)

For one start it takes 20 minutes for an ambulance to come, that's emergency, like that's between death and life. For two it's thirteen miles for the nearest hospital.

(Female, 28, Local Authority site)

If you didn't have a car you would be bloody up the spout. Because you couldn't expect the GP every time you've got something wrong with you to keep coming out.

(Female, 30, Local Authority site)

Housed Travellers generally have better access to the wider community as they often live quite close to a GP's surgery, other public services and amenities, and commonly cite this as a benefit of living in a house rather than on a site.

James and Sonia, 30s, English Romany, housed

James and Sonia and their six children, all under the age of nine, have been housed for five months (after six months on a waiting list) and previously lived on a local authority site. They moved due to a lack of space in their caravan, coldness in the winter (heating bills were very expensive) and having to use outside toilets.

They prefer living in a house as there is more space for the children to play in, whereas it was unsafe to do so on the site, where one of their daughters was knocked down by a visitor's car. It also means they are closer to their GP and they no longer have to rely on lifts as they can walk there. They are very happy with the doctor and also receive visits from the Health Visitor. They are sent reminders from the GP surgery but would prefer phone calls – James can read but Sonia cannot and the kids sometimes pinch the letters and draw all over them.

They try to stay healthy by going for lots of walks and eating healthily (fruit and vegetables). Both of them smoke, Sonia heavily, although she tried to cut down when she was pregnant. John used patches to try to quit but said they did not work.

They feel generally quite healthy as a family. James suffers from migraines and asthma, as does one of their daughters. Heart disease runs in Sonia's family and she worries that her children may also have similar problems. Sonia used to take pills for bad headaches which her doctor said could have been post-natal depression.

James sometimes cares for his 31 year old brother, who has Down's syndrome and lives on a local authority site with his mother. James will help by cooking him meals and he stayed with them for a few weeks when the mother was away. They have been offered support to help with his care but they would prefer to keep it in the family rather than depending on other people.

5.2 The lifestyle of Gypsies and Travellers in Mid Essex

The fieldwork raises a number of key lifestyle issues for the Gypsy and Traveller population in Mid Essex, which broadly reflect the findings of the literature review and the stakeholder interviews. In this section we will discuss:

- the meaning of health to Gypsies and Travellers;
- diet and exercise;
- drinking alcohol;
- smoking; and
- stress.

5.2.1 The meaning of health to Gypsies and Travellers

Generally, health is not something which the individuals we spoke with worried about or spent much time thinking about day-to-day. Health comes after financial and family matters

on individuals' lists of priorities, and the health of their children and wider families is more important than their own health. Women in particular worry about the health and wellbeing of their children, which leads to anxiety and a tendency to ignore their own health. Men are even less concerned about their own health, and were more reluctant to discuss health at all.

There is some awareness of what a 'healthy lifestyle' entails amongst Gypsies and Travellers in Mid Essex, such as 'being outside' and 'being active', and some pro-activity in terms of eating healthily and taking exercise. However, this awareness seems to concentrate itself in much older members of the community who talk about healthy eating and exercise in some detail.

We do a lot of walking. We keep healthy, you know what I mean?

(Male, aged 70+, Private Site)

There seems to be little interest in lifestyle issues for many, and an inability to articulate what a 'healthy lifestyle' is. Most do not seem to link lifestyle with health, or the particular conditions suffered by themselves or the people around them.

5.2.2 Diet and exercise

Some of the women enjoy cooking meals using fresh ingredients and pay attention to eating fruits and vegetables – for a few this is out of the sense of duty to their family; others appear to live on food high in fat and salt, and eat few fruits and vegetables. Some participants feel that they are 'supposed to' eat fruits and vegetables, and believe that they should eat more fruits and vegetables, though they do not articulate why this is the case.

I'd have the large chips, two steak and kidney pies and two cans of Coke. I'd probably have a big cream cake for my afters, and things like that.

(Male, aged 40+, Local Authority site)

I'll make him probably sausages, bacon, beans, but that's not an everyday thing because I don't like a fried breakfast in the morning, it's too greasy for him, and especially with the pains he gets in his chest, I do be afraid, because he does suffer an awful lot of pains in his chest, I do be afraid sometimes. But it'd give him an awful lot of grease, so I'd rather give him porridge or two Weetabix, I know it's healthier for him.

(Female, aged 20, Local Authority site)

Many of the men seem to live fairly active lifestyles, mainly because of their work.

Yeah I'm always outside and getting wheelbarrows and I'm up and down. So it's more like exercise.

(Male, aged 40+, Local Authority site)

However, Gypsy and Traveller women are generally more less active, spending most of their time on-site with family and neighbours, their only physical activity being housework. Limited access to and from sites, as discussed above, influences women's ability to access healthy food and opportunities for exercise, which has health implications for their children as well as for the women themselves. Few of the individuals we spoke with undertake any exercise with a view to keeping fit or losing weight, and few are concerned about their weight for either health or aesthetic reasons.

Some of the older Gypsies and Travellers are troubled by the decline of the traditional lifestyle, which was much more active when travelling was an essential part of the lifestyle, and included farming and hunting, and the cooking of meals from fresh ingredients. They link the decline of this lifestyle to a decline in the wellbeing of Gypsy and Traveller communities.

The food we used to eat years ago, because we used to live on what we caught... It was rabbit's, hares, pheasants, deers. Whatever we killed, we used to eat. Most people now haven't got this food, food that, they eat, the wrong food they eat, like Chinese, Indian. You don't know what goes into it. A lot of people eat the wrong kinds of food now. A lot do, like my grandchildren. They've started eating all the junk food, but I told them, it ain't no good for them.

(Male, aged 80+, Private Site)

5.2.3 Drinking alcohol

Whilst Irish Travellers tend to drink alcohol only on special occasions, drinking alcohol is something which the men in the English Gypsy community seem to do regularly and heavily. A vital part of their everyday lives, they do not consider this to be unhealthy.

I've drunk near all my life. I've drunk enough beer to float a ship. I've drunk 20 pints of beer every day of my life nearly, but beer don't hurt you.

(Male, aged 80+, Private Site)

Men discussed their drinking with us voluntarily but we also got a great deal of information about drinking from the women we spoke with. One woman mentioned her brother's drinking, and the impact that it had on the management of his diabetes. Whilst some expressed that drinking could be a problem in this way, none used the terms 'drinking

problem' or 'alcoholic', and it seems that to describe drinking habits in this way is taboo, much like 'mental health' issues, discussed in more detail below.

Women in the Gypsy and Traveller communities rarely drink, except for on special occasions when they will have a small amount of alcohol. Abstinence from drinking does not seem to be linked to a desire to be healthy but is associated with the social stigma attached to women who drink.

Darren, 16, English Gypsy, housed

Darren lives with his mum, and his younger brothers and sisters in a house and has been there for a couple of years. They have lived all over the UK and used to live on a local authority site but moved away because his parents split up. As soon as he can drive he will leave and get a caravan.

He is taking a landscape gardening course at the local college, to 'get some qualifications and papers' and does a little bit of work for his grandfather.

He does drink alcohol but only at Christmas, New Years or if there is a party. He does not drink much, because he 'doesn't know when to stop'. He has smoked since he was 14 and did give up for a while (using NRT patches) but he started again after he went to Ireland as it was boring!

He feels ok about his health but thinks he needs to go to the gym because he is 'not very fit running-wise' and doesn't really do much exercise. He walks a lot with friends though when he goes to see them in London. "The past couple of months I've been saying I'll go to the gym next week, I'll go next week, but it just aint happening. I went to the gym but it was too dear". The college gym is only £2 per session but feels he just needs to start going and to get into a routine.

He has had non-Traveller girlfriends but only to "mess about with" and will settle down with a Traveller girl. He uses condoms and would see the doctor if he had a problem with sexual health "I'd go straight up the doctors, I wouldn't be ashamed to go there".

5.2.3 Smoking

All but a very small number of the individuals we spoke with smoke heavily, despite believing that smoking is a "dirty habit". This includes those with long term health conditions and pregnant women (although most claim they did try to cut down when pregnant). Smoking is strongly linked with the relief of stress for most participants (this is discussed in more detail in the next section).

I smoke, just, yeah, I do smoke, which is not a proud thing, but I have tried to stop it, but I can't. I end up climbing the walls. Well as soon as I get worry or stress that's the first thing I go for, the fags.

(Female, aged 34, Housed)

Yeah it calms your nerves doesn't it? Cigarettes. Like through the day, I don't smoke hardly that much first thing in the morning, I have at least four or five fags before I get into bed. It's a bad thing really.

(Male, aged 40+, Local Authority Site)

Many believe that smoking is 'bad' but are unable to explain why this as, and they do not seem to make the link between smoking and the long term health conditions suffered by themselves, their families and their communities. A few had tried to quit smoking but had failed, attributing this to stress and a lack of real will to do so. Many were not unduly concerned about even second hand smoke affecting their children – some women felt it was not an issue because they opened all the windows when they had a cigarette.

Well I know, someone told me about patches and things like that, but to be honest, I've never ever tried them. I've never really sat and thought, I'm going to stop it. I've not really got to that stage where I really want to do it.

(Female, aged 34, housed)

There was a sense that the consequences of stress were much more serious than the consequences of smoking.

You do get a little bit of a cough, but it'd be worser for me to give them up now. It's like my brother, he was smoking all his life and then he give them up then for a year, he broke out in ulcers, his chest come very bad against him, because he was that used to the nicotine. And the doctor told him that it was better to go back on them, because he got too ill of it, you know what I mean?

(Female, 20+, Private Site)

Few of the people we spoke with have been offered or sought the support of smoking cessation services in their attempts to quit. Some have heard of NRT 'patches' but had not pursued this avenue in their attempt to quit, but think that they might do so in the future. One or two have tried patches or nicotine replacement gum but feel that it was not very helpful.

If I knew it [nicotine patches] was going to 100% work I would use it, yeah, I would ...I would use them, I'd like to give it back up and finish it.

(Male, aged 45, Local Authority site)

With smoking prevalence so high, it is difficult for many (particularly those living on sites) to remove themselves from a smoking environment and, therefore, temptation. Moreover, smoking is so ingrained as a community norm, and stress levels so high amongst many members, that the barriers to quitting are immense.

5.2.4 Stress

Mental health was an area where we expected to have particular difficulty in interviewing people as a result of the stigma attached to mental health conditions and the tendency,

therefore, to under report and shy away from discussing them. As expected, we found that many do not like to use terms like 'mental health' or 'depression' and men in particular are reluctant to talk about mental health, though they do feel that it is easier to discuss with 'outsiders' than with their wives or families. However, we found that most of the women are happy to discuss stress and anxiety, and indeed do so as if it is a normal and inevitable aspect of life.

Paul, 45, English Gypsy, Local Authority site

Paul has lived on his site for 15 years after moving out of London. He has eight children (three of school age) and seven grandchildren and his girlfriend lives in the caravan next door to him. He is self-employed in the scrap metal trade.

Paul smokes quite heavily and has tried using NRT patches to give up but they didn't work as he 'hasn't got the will-power' to quit. He admits he drinks too much alcohol but he has tried to cut down the amount of food he eats as suggested by his doctor. He has lost three and a half stone (and now weighs 19 and a half stone) by eating three meals a day rather than snacking and eating a lot in the evening. He also eats weight-watchers bread, after his brother told him it was healthier.

Paul has high blood pressure, and realises that his lifestyle does not help. He has regular three-monthly check-ups, and receives reminders which he thinks are useful. However, he would not visit the doctor for ill-health unless he was very ill and could not get out of bed.

He has suffered a lot of deaths of close family members recently, mainly due to heart disease which runs in the family. Consequently, and combined with worrying about his and his girlfriend's health (who suffered severe pain in her back, and temporary paralysis which remains undiagnosed) he suffers from depression but does not want to receive help offered by his GP, or take any sort of medication, as he wants to deal with it on his own.

Paul is very favourable about the GP services he has received and appreciates the help they offer. He had not previously heard of NHS Direct but thought it was a good idea and a service he would use, for 'someone to talk to'.

There are high levels of bereavement in Gypsy and Traveller communities – most of the participants had experienced losses of friends, spouses, neighbours and – particularly striking – children, as well as the elderly,. They also experience stresses associated with financial matters and living on sites and/or moving from sites into houses. In addition, women in particular (but not exclusively) are quite open about the stress and worry they experience in relation to their children, particularly those who had children at high school and were themselves experiencing anxiety, both about growing up and their experiences of discrimination and bullying. There was also some mention of postnatal depression (but seems to have gone untreated).

I'm a worrier man, I worry a lot, about the family, my kids and things, like I say I've got kids all over the country, I've got kids in Scotland, kids like Swindon, some's in Wales, they got married to different people, and some got married to Scots people, some got

married to Irish people, some got married to Welsh, so they're all around... and it worries you a lot, and you can't help it, like say when you're a father, you're a dad and that, you can't help worrying. And things like that do get to you but you just try to get through life.

(Male, aged 40, private site)

Treatment for mental health conditions is rarely sought outside of the community. People identified their own ways of coping with stress, such as smoking (as discussed in the section above).

I'm a heavy smoker, very, very heavy smoker because what's gone on for the last year over my cousin dying and over my brother's child dying, that's why I've gone so heavy for smoking.

(Female, aged 20, Local Authority site)

Gypsies and Travellers also feel strongly that their families should be the primary providers of advice and support, and that externally provided 'talking therapies' were undesirable.

If I get stressed I just talk to my friends rather than [a counsellor]. Not that it makes it [all better], but if you've got someone to talk to it do a little bit. You think oh it ain't so bad, and they'll say oh we'll do this, or don't worry, or... So I've always got the phone on, so I can always ring somebody.

(Female, aged 34, housed)

5.3 Health issues specific to women

There are a number of health issues specific to women, such as family planning, pregnancy, breast feeding, and sexual health and screening which we were able to discuss with some women during the fieldwork.

5.3.1 Family planning

Gypsy and Traveller women tend to have a large number of children and to start doing so at a young age (as young as 16). However, we spoke with some women (and their husbands) who are open to family planning, and had smaller families at an older age. Women from these families often use the pill as birth control but do not seem to be in favour of the injection or the coil as they have heard of other women having bad experiences with these methods. None of the women we spoke with use condoms as they feel that their husbands would not agree to do so and they do not feel that they are at risk of sexually transmitted diseases.

5.3.2 Pregnancy

We spoke with a number of pregnant women from a range of age groups and at various stages in their pregnancies. Some were having a good experience of pregnancy and were generally positive experiences of the care they were receiving (this will be elaborated upon in detail in the section on service access below). They had few concerns about their health or the health of their babies. One woman was undergoing tests for diabetes as diabetes was in her family, though she did not seem to be concerned about this. Some women mentioned problems with pregnancy, such as pains or cysts, but had not been to the doctor as they felt uncomfortable discussing it with a male. Few of the pregnant women were attending ante-natal classes or knew what to expect from childbirth, but most were excited about the prospect, and a few women that we spoke to were clear about the need to attend their GP surgery for “booking –in” and a three month check-up. All of the pregnant women we spoke to smoke, and had continued to smoke throughout their pregnancy. They tended to think that this was ‘bad’ but were unable to articulate why this was the case.

Yeah I smoke and I know I shouldn't smoke. I'm not so much worried about me, I'm worried about the baby. But I've cut down.

(Female, aged 30, private site)

Sally-Ann, 23, Irish Traveller, Local Authority site

Sally-Ann lives in her ‘shed’, as she calls it, with her three year old daughter. Her husband is an English Gypsy, but he isn’t around much; she thought he was back for good last year, but he left again. She is a bit worried about this as she is pregnant at the moment, but is looking forward to the birth as she ‘loves children to bits’.

Sally-Ann feels pretty good about her health, but she does worry about having enough money to give the children healthy food as she only get her Income Support; she’s not sure about other benefits. She can’t get out walking much these days as the road to the village doesn’t have a pavement for the pushchair. She does smoke, but doesn’t think she needs to give up. It calms her nerves, and at least she doesn’t drink. Anyway, she makes sure her kids aren’t breathing too much in by opening the windows when she has a cigarette.

Sally has been through a lot recently; she found out she and her husband have different kinds of blood, so she has to have injections every few months to make sure the baby is ok. She has been through this once before though, so this time around she can manage, it’s just hard to remember when she has to go for her appointments. She’s been having pains in her sides too, but doesn’t really want to see her GP as she feels uncomfortable telling a man about women’s things. She might go if it gets really bad but by the time she gets an appointment with the female GP it’ll probably have sorted itself out.

Sally-Ann recently lost a niece who she looked after as her own – she suffered from aplastic anaemia and died. Sally accepts that God called her back to him, but wishes that the doctors could have done more, or at least told her to expect the worst so the family could all go visit the hospital to say goodbye. Her sleeping can be troubled, and some days she cries a lot, but she doesn’t want to take pills because she needs to look after her daughter. She has the support of her cousin who lives in the shed next door. Her cousin knows what she is going through – she just had a miscarriage, and her husband isn’t around either.

Gypsy and Traveller men do not get involved with pregnancy in that they do not discuss it or attend the birth itself. The reasons for men not attending the birth of their children seems to be around the women not wanting their husbands to see them in labour, and the potential embarrassment for other female birthing partners such as their mothers.

I wouldn't feel comfortable with my mum and my husband in there while my legs are wide apart.

(Female, aged 30, private site)

5.3.3 Breast feeding

Embarrassment is also an issue when it comes to breastfeeding, though this seems to be linked less to women not wanting their husbands or other family members to witness them breastfeeding and more to do with a feeling that breastfeeding in public is undignified.

No, we don't breast feed, no. Travellers don't. When your child has to be fed it has to be fed, hasn't it? And you're not going to pull out your tits every time you go to deal with it. And god knows where you'd be. It's nice me sitting here and three or four men going... It's not nice.

(Female, ages 24, private site)

I think it's embarrassing. If you're out and you're shopping or you're going visiting. Just pulling your breast out like that, I think it's very inappropriate really. I think if you want to breast feed, things like that should be done in the privacy of your own home.

(Female, aged 30, private site)

Gypsy and Traveller women do not seem to be aware of any debate around the merits of bottle feeding versus breast feeding, and the decision for them to bottle feed their babies seems to have been automatic and led by cultural norms.

5.3.4 Sexual health and screening

Gypsy and Traveller women do not tend to feel that sexual health is an issue for them as they do not have sex until they are married. Some of the younger women have received Chlamydia screening kits but they threw them away as they do not believe that they are relevant to them¹². Attitudes towards cervical screening are mixed. Attendance seems to be

¹² Nor was sexual health an issue that was easy to discuss with men. However, one younger man who was not yet married did explain that he had non-Traveller girlfriends but sees himself settling down with a Traveller girl. He saw his relationships with non-Traveller girls as being 'a bit of fun' whereas Traveller girls 'want you to marry them' – this reflects what we found in the literature review and stakeholder interviews.

good amongst those who are more settled, more literate, had a regular GP and felt comfortable accessing services. Some have had scares with abnormal cells or other conditions in the past which means that they go for regular screening. Others have never been for cervical screening and feel scared of going which leads them to put it off. There is little knowledge about what cervical screening is for, though the news and television coverage of Jade Goody's cervical cancer had led a few to believe that they should go for screening.

No, never had one. They often do tell me [should] go for one, but I just never got around to doing it. Jade made me want to go and get one done, but, so I just never had one in my life. If I feel sick I'll go and see a doctor, but other than that... [The Jade thing] led me into what [cervical screening] was, and why it should be done and all this stuff. So I will one day, some day. My mother was telling me, because when the story come up, I'd asked, what is that? What did she get? How did she get it?
(Female, aged 30+, Private Site)

5.4 Accessing healthcare

The ways in which Gypsy and Travelling communities approach healthcare and access healthcare services will be discussed in this section. All of the participants in the research were registered with a GP, which is probably due to long-term settlement in the area. Furthermore, local authority-run sites actively encourage registration with GPs, the site manager ensuring that new residents are aware of local services and how they can register, even filling in forms if required. Many housed Travellers feel that better access to services such as health and education are good reasons for moving into a house.

However, this does not necessarily mean that access to healthcare is always easy for Gypsies and Travellers. Most of the participants in the research have long term health conditions and there are a number of tendencies, deriving from the overarching features of the Gypsy and Traveller communities in Mid Essex (discussed in the first section of this chapter) which seem to act as a barrier to their accessing services. These are:

- The under-reporting the severity of health conditions
- The acknowledgement of health conditions only when they reach crisis point
- The responsibility of families to care and administer medication

In this section we will discuss the influence of these factors, and others on Gypsies' and Travellers' access to healthcare, and the perceptions of the quality of healthcare they have received.

5.4.1 Attitudes towards visiting GPs

Although registration with GPs was consistent, and had not posed problems for most of the individuals we spoke with, the use of GPs varied considerably depending on gender, age and whether the individual was suffering from any long-term health conditions.

Louisa, 32, English Gypsy, housed

Louisa lives in a nice big ground floor flat in Chelmsford with her four children. Two are in the 'terrible teenage phase', one is nine, and her youngest is two this year. She has a different dad though – the others' dad was Irish but he was really cruel when he started drinking.

She likes their house for the moment, because there's lots in town for the kids to do, there's a good college for her eldest ones to go to and that, but she feels a bit cooped up. Given the choice, she'd buy up her own piece of land and stick a caravan on that – fresh air and no neighbours complaining about council tenants.

She looks after her health. She makes sure she gets regular smear tests, as she had a friend that had cancer and died, and she had abnormal cells a few years ago. She has had to sort her children's vaccinations out recently, because they used to move around so much they weren't in school when they should have had the BCG and the MMR. But the GP they go to is great - they know that they are Gypsies but they don't make a big deal about it.

Her family, touch wood, are all in good health, although the two eldest started smoking recently. Her second son keeps getting stomach aches at school and wanting to come home, but she's not sure if he's pretending as he seems fine when he gets in. He is a bit on the heavy side though - the doctor has suggested he go to Junior Live Life classes where they do lots of activities after school.

Past experiences are very important in forming the views of Gypsies and Travellers about health services and where treatments have not worked, word seems to have spread quickly among friends and family and resulted in the distrust of doctors and their advice. A very small number claim that they would be unlikely to go to their doctor in the future as a result of these reports or their own past experiences. This attitude is exacerbated by the lack of alternative information Gypsy and Traveller communities seem to have about health services and health matters.

Women, as guardians of their families' health, tend to access GP services more readily than men, although this will often be for their children's health rather than their own.

If they get a little cold I rush them straight to the doctors. To me I'd rather be safe than sorry, not to get them medicine or anything, just to make sure they're all right.
(Female, 30s, housed)

As we have discussed throughout this report, stoicism and independence are important aspects of male Gypsies' and Travellers' lives and many will only seek care for themselves

when they perceive the need to be urgent and they feel that they have no other option. This is coupled with a reluctance to 'bother' their doctor.

Very rare I'll go to [the doctor], I've got to be really ill to go to a doctor so, well once in five year I suppose, if that... That's the way I was brought up I suppose. I haven't had tablets and things like that... Yeah if I think I can work it off myself then I don't worry.

(Male, aged 50, Local Authority site)

Being a Gypsy bloke I feel embarrassed all the time to go to the doctor's.... My doctor said, no need to be embarrassed mate, because we can help you. I said, I know, but I try to deal with my things in my own way.

(Male, aged 50, Local Authority site)

We do find it funny sitting in a doctor's surgery, we only go if we have to, or we feel that we have to, and it's usually just leaving a thing till you feel you need a bit of help with cutting something open or whatever the case may be.

(Male, aged 77, Local Authority site)

This often leads to the need for emergency services – some of the men we spoke with said that they have to be unable to get out of bed before they seek help.

In my case I wouldn't go until I really have to, because that's the way I am. Another bloke you get a pain and you go but I won't. Like when I go to hospital I've got to be on my back bad, and carted out... apart from that I would not bother to go.

(Male, 45, Local authority site)

A common feeling was that Gypsy and Traveller men would rather deal with things themselves instead of seeking help elsewhere.

I don't have flu injections, never need them. Sometimes I get the flu but I don't have them, haven't had it so far, two years. [I] go and get some bottles of wine and a belly full of beer, and pour some wine down there so I can go and have a good sleep, and as a rule that does the trick.

(Male, 77, Local authority site)

I'll probably have a Lemsip or something like that or a cup of OXO, the old way around, a cup of OXO and plenty of pepper and sweat it out of me, and go to work and sweat it out again.

(Male, 50, Local Authority site)

This desire to be self-reliant is particularly strong for things like mental health problems, for which medication is rarely sought.

Although the actual management of long-term health conditions does not seem to always be well controlled as a result of reluctance to go to the doctor or difficulty keeping on top of

medications, those (particularly the elderly) who do suffer with long-term health conditions like diabetes, seem to be more likely to go to the GP for a general 'check-up' if they are required to make regular visits to the GP to get a prescription.

5.4.2 Health Visitors

Health Visitors to mothers of young children are strongly appreciated. This service is seen as extremely important for the health of the young child, but also as a means of emotional support, advice and a trusted avenue of information for the mother. One woman explained that her Health Visitor helped her get through the cot death of her second child.

However, in some cases calls from Health Visitors had lapsed either because the mother had travelled away from the site or the Health Visitor had left their post and not been replaced. There is some confusion in the Gypsy and Travelling community over the time that Health Visitors should continue making trips to see patients, some believing it is until they are two years of age, others five and some seven, which suggests inconsistency in the provision of the service across the Gypsy and Travelling communities.

5.4.3 Use of Accident and Emergency (A&E)

Use of A&E inappropriately appears to be less of an issue in Mid Essex than elsewhere in the UK (as reported on a national basis in the literature review), since most of the Gypsies and Travellers who live on sites seem to be registered with a GP and only a few pass through the area on a temporary basis.

Due to the lack of data that is collected specifically on Gypsies and Travellers in A&E departments (ethnicity is often not recorded as it is dependent on the individual being willing to provide it), information about the number or nature of visits to A&E (and whether they might therefore be inappropriate visits), is limited to the anecdotal. However, staff at Broomfield A&E report that, as a 'gut feeling', attendance for minor complaints is not a significant issue for them and that the majority of cases legitimately require A&E treatment. It should be noted, however, that this in itself could possibly be a false view as the identity of Gypsies and Travellers can often be hidden.

Where use of A&E is common, it is often because individuals become ill outside of GP surgery hours or if their problem is particularly urgent and they cannot get a GP appointment

quickly enough. This does seem to be a particular issue for Gypsies and Travellers, especially those who leave reporting illness until crisis point.

5.4.4 Dentistry and optometry

The use of dentistry services seems to be limited, with most only seeking treatment when it is urgent - to get a filling or have a tooth removed. This is largely because of the cost involved but also because, like their health management generally, the health behaviour of Gypsies and Travellers is often reactive and lacking in preventative awareness.

It also seems that for some there is a general lack of awareness of the other health services which are available.

Well the dentist and the eye place I've never like bothered with all that business, so I don't know really much about that.

(Male, aged 45, Local authority site)

However, there was some evidence that younger generations are more likely to go to the dentist proactively and some had had orthodontic treatment.

5.4.5 The quality of services received

The quality of healthcare services received by Gypsy and Traveller communities in Mid Essex is generally felt to be good. The areas where problems in service access and service quality do occur are discussed in detail in this section.

Health professionals' understanding of Gypsy and Traveller culture

Generally it would appear that many problems in treatment occur where medical professionals lack an intuitive understanding of Gypsy and Traveller culture. Medical professionals can be in a difficult position on this matter, as Gypsies and Travellers are not an immediately visible minority and often will not volunteer their ethnic background. These issues do, however, need to be addressed, as there is a risk that an unwittingly insensitive approach to something apparently peripheral such as visiting rights can actually affect a patient's willingness to seek treatment in the first place.

I'd been [to hospital] before... the only problem I did have is when they gave me the needle. They won't allow anyone in with you, you have to do that alone. You could have nobody in with you, [not even] my mum, my sister. That's why I [got] nervous [and caused a scene].

(Female, aged 30, Local Authority site)

When something happens to one of our kids, there is about ten, twenty girls travelling girls there with you, make sure the kid was OK. It's only for support, doctors don't like that - just the mother, that's what they'll say, so that's difficult. We're very supportive with our own community. You're going to get kicked out, so you've to go and tell your friends, they probably drive 200 and 300 mile, that they can't come in and see you.... that's why you won't see much of us going to a hospital now because we're afraid in case the person that's sick is getting kicked out of the hospital.

(Female, aged 26, Local Authority site)

Trust in health professionals and an established personal relationship appear to be key to developing an understanding which encourages Gypsy and Traveller individuals to seek medical care. Whilst this is not in itself a cultural issue, Gypsies and Travellers tend to move more frequently than most, or at least travel for some months of the year, which sometimes has a limiting effect on their ability to develop and maintain trusting personal relationships with medical professionals. There can also be difficulties in getting temporary registrations with GPs whilst travelling, although this is most often dealt with by accessing the GP who knows the family member they are staying with well.

Sensitivities around the gender of healthcare professionals

In some circumstances women can be quite nervous about approaching GPs. Women will usually be averse to approaching a male GP about intimate problems and may only do it when they believe the problem is serious.

There is an awful lot of men in the GP [surgery] for us it's kind of embarrassing. Last year I had some lumps in my breast that I understood it was a bad thing. I had to take off my bra, and two men, one hand this side of me, and the other hand this side of me. When it comes like pregnancy or monthlies, you're like, kind of embarrassed to tell them. Like if it were a woman you'd come out with it all, wouldn't you?

(Female, aged 26+, Local Authority site)

When I had a miscarriage after Christmas I went off to the maternity hospital, I asked for a woman doctor to examine me, and he told me, if I didn't want to get examined, go [home], all because I asked for a woman doctor, because us women Travellers don't believe in a doctor man touching our breasts or [other places], because our husbands don't like it.

(Female, aged 24+, Local Authority site)

Whilst most of the women we spoke to seem to know that it is possible to request a female GP, they feel that there are not enough female staff at their local GP practices (often small rural health centres) to make this realistic without waiting a long time for an appointment.

Whilst women are willing to present to a male doctor should they have no choice, they will normally only do so when the problem has become serious and unavoidable. This may mean that many Gypsy and Traveller women do not seek early preventative treatment and when they do present, that they only give partial explanations of their symptoms to a male doctor, which may risk misdiagnosis.

Discrimination on the part of healthcare professionals

Throughout this research there was relatively little mention of discrimination, with most believing they are treated as 'normal patients' and that the situation has improved dramatically in recent years. Indeed, health services in the area were often considered to be more accommodating than many other services in the area, such as local pubs or shops. However, there was some experience of what was thought to be unfair treatment with regards to travelling in large numbers to hospitals (as mentioned above) and there were some reports of ambulances refusing to travel onto Gypsy and Traveller sites without a police escort.

It should be noted that Stakeholders from the ambulance service believe that relations between Gypsy and Traveller communities and the ambulance service had improved in recent years and that a lot of progress has been made in reversing preconceptions about Gypsies and Travellers. While in the past there have been cases of ambulances refusing to enter sites without a police escort, this will now only happen if the call involves an occurrence of violence, as would be the case in any other community.

With regards to literacy and completing hospital forms, staff were generally felt to be helpful, although there were isolated cases cited where it was thought that some receptionists and medical staff could be a little more understanding of those who cannot read or write.

When it comes to sitting down and trying to fill a form in, I'm no good and I've said to them, I said to one of them like, I can't fill it in, could you help me? And she said, no, we're not meant to do that, you've got to do that yourself. So that's a bit off putting to be honest.

(Female, aged 30+, housed)

Similarly, the ability of doctors and nurses to explain things such as diagnoses and medications in a simple, non-technical way was mentioned as being invaluable, both to increase understanding of the condition and its treatment but also to positive patient experience.

They [hospital staff] tell you what's what...in a normal way, because I don't understand these posh words.

(Female, aged 30+, housed)

5.4.6 Onsite versus offsite healthcare

For the most part, Gypsies and Travellers do not seem to feel that there is a need for health services to be provided specifically for their communities on-site. Most were content to access services currently available to them and the only instance in which people feel that there is a need for onsite provision is for the vulnerable, elderly or immobile.

As well as Health Visitors, as discussed above, other services making specific visits to the sites included blood pressure testing vans. Site managers of Council-run sites are important in explaining the purpose of these and encouraging participation. One site manager told us how she answered resident's questions and explained that it would not involve the taking of any blood or an injection before people took part. One improvement which was suggested was that the particular dates and times of these visits should be better advertised so that people could make sure they were on-site.

5.5 Access to information about health

Most participants in the research feel they are sufficiently informed about health and health services, although no one could cite any other source of information outside of GPs and Health Visitors. Furthermore, it was clear that there are some areas where health awareness is quite limited and that many of the means used for advertising health-related matters were unsuitable for Gypsy and Travelling communities.

Where would you go to get another help [other than GP]? We can't read or write, we can't find help.

(Female, aged 20, Local Authority site)

The role of the site manager (on Local Authority run sites) is an important trusted source of information, for instance helping new residents register with GPs or letting them know about services such as the mobile blood pressure testing vans. It is therefore vital that these 'information gatekeepers' are fully informed and do not reinforce myths about health or health services. Those living on private sites miss out on this source of information.

5.6.1 NHS Direct

Awareness of NHS Direct is very low among Gypsies and Travellers in Mid Essex, with most not having heard of it. However, the idea of a telephone number they could call if they had a query about health was very positively received (in fact, many took the number during the interview). Once explained, the idea appealed to people as a way to get simple advice without having to arrange a doctor's appointment or at times when the GP surgery is closed. It was also thought to be beneficial for those who would not normally go to the doctors or who had poor literacy and therefore had limited access to written information.

I would have to be suffering to go to the doctors or whatever, so I could ring them up on the phone and explain to them what I'm like and they'll probably say, you'll have to come in, and I'll think, well I have to go in now because I've told them I would and I'll tell them why. Because I can't read or write you see, that's my problem.

(Male, aged 50, Local Authority site)

It was also thought to be appropriate for more technical matters and those living with long-term health conditions.

I think it is a handy line to have. If you're not quite sure of giving someone an injection or something, because I have to inject my wife, and if I got stuck or whatever and I wasn't quite sure what I had to do then I would ring that number so I could get advice how to approach the problem.

(Male, aged 47, housed)

Web-based tools, such as the NHS Choices website are thought to be far less suitable, due to low levels of literacy and lack of access to the internet. While most housed Travellers and some of the sites have telephone landlines, no participant in this research had access to the internet.

5.6.2 Reminders

Reminders for doctor and hospital appointments are thought to be helpful.

I do forget a lot, I mean I put something down then forget it, and then realise, bloody hell the appointment's up, and realise it. But they send me a letter the week before, then it comes along, say, oh bloody hell, yeah they look after us that way, they really do yeah.

(Male, aged 45, Local Authority site)

Where letters are received they will often be read by a literate friend or family member if the individual themselves cannot read. For this reason, NHS logos or further iconography are important for making it clear that the letter is important and should not be thrown away.

Some preferred phone calls, partly due to literacy problems but also because of problems with accuracy of the postal service and keeping the letter somewhere safe once it is received.

Sometimes you will not get your mail on this site. So even if an appointment do come out you might miss it...A phone call'd be better because I can't read or write.
(Female, aged 20, Local Authority site)

Well to be honest I reckon phone calls is better because like I said to you, they [young children] get hold of the letters and they write all over it. So the phone calls is better to be honest.

(Female, aged 30+, housed)

In this chapter we have discussed the overriding concepts which affect the health-related attitudes and behaviour of Gypsy and Travelling communities in Mid Essex, including gender roles, the importance of the family and independence from the 'settled community', fatalism, and the environmental impacts on health. In addition we have discussed particular lifestyle issues in the Gypsy and Traveller communities in Mid Essex, such as the incidence of smoking, poor diets and the less active lifestyle led by women, as well as the impacts of stress on health and wellbeing. Finally we have discussed access to healthcare and perspectives on the quality of healthcare services from the Gypsy and Traveller community. In the next chapter we will draw on these findings and present a number of recommendations for health-related interventions NHS Mid Essex might wish to consider.

Recommendations for interventions

6. Recommendations for interventions

Above we have observed the health needs of Gypsies and Travellers in Mid Essex both in terms of lifestyle and service access, and have demonstrated some of the barriers and enablers to the health inequalities experienced by these groups in the Mid Essex area. In this section we put forward our recommendations for interventions which might be implemented to tackle some of the health issues we have described. The interventions we propose should not be treated as 'one-size-fits all' – the Gypsy and Traveller communities in Mid Essex are diverse and differ on sites as well as between them, which means that interventions will have to be tested for appropriateness with each group in each location. None of the interventions we propose are without risk, and these will be described alongside the benefits of our suggestions below. We highly recommend that any intervention implemented is done so with the consultation and consent of the communities involved, and piloted before it is rolled out more widely.

The interventions have been set out under three broad headings – 'improving lifestyle and health-related behaviours', 'improving access to services' and 'structural changes needed to promote healthy lifestyles and good access to services'. The suggestions in the first two sections should be possible for NHS Mid Essex to action independently and quickly. However, to implement some of the suggestions in the final section it will be necessary for a joint approach involving a number of agencies operating in the Mid Essex area, and will require relationship building and lobbying for action to occur. Our experience in carrying out this research has shown us that where unauthorised encampments are concerned it will be difficult to move beyond the opportunistic in the interventions developed, and will require excellent communication between the PCT, the TES and other bodies responsible in tracking and counting caravans in the Mid Essex area. Those who live at least semi-permanently on local authority or private sites will be easier to target with more complex interventions, and are the main focus of the suggestions which follow.

Some of the points which we feel are the most crucial to keep in mind when developing interventions for the Gypsy and Traveller communities in Mid Essex are:

- The central role of women in the health of the family
- The importance of hearsay and word-of-mouth for circulating messages
- Poor levels of literacy in the Gypsy and Traveller communities

6.1 Improving lifestyle and health-related behaviours

6.1.1 Targeting single issues

The research has found that awareness of – and lack of concern about – health related behaviours is poor amongst Gypsy and Travelling communities, and we would therefore suggest that **single-issue campaigns and interventions** which might move communities from the ‘pre-contemplation’ stage of the behaviour change model to the ‘contemplation stage’, where people are considering changing their behaviour. Any campaign developed must meet the needs of the community it is aimed at, and for Gypsies and Travellers any campaign must take into account low literacy levels in the community which might prevent written messages from getting through. Verbal messages are probably the best form of communication with the Gypsy and Traveller communities in Mid Essex. However, these messages might be lost if they are not delivered by a trusted source, such as a respected member of the community itself or a regular health worker. Who delivers messages, a community member or an ‘outsider’ might depend on the subject matter of the intervention – on very intimate matters we have found that Gypsies and Travellers often feel more comfortable with an outsider, whereas on some matters, such as vaccinations, people trust information from within the community rather than from outside of it.

Below we have listed a number of suggestions for single-issue campaigns and interventions:

- An **awareness-increasing exercise around the harmful effects of smoking**, linking smoking to the long-term health conditions which are suffered by many members of the Gypsy and Traveller communities in Mid Essex. This should occur alongside awareness-raising of the help available to quit smoking, such as NRT, for those who are already at the ‘contemplation’ stage, and potentially on-site provision of these cessation services. For this to be effective it is crucial that Gypsy and Traveller communities are presented with alternative ways of dealing with stress. In addition, because of the importance of hearsay and word-of mouth in the Gypsy and Traveller communities, it might be most effective if these messages come from those in the community who have stopped smoking themselves.
- It would also be helpful to **raise awareness of the benefits of healthy eating and exercise**, and to make mothers aware of benefits which are already available to them, such as vouchers for milk, fruit and vegetables, and healthy-eating cookery courses which should be made available through self-referral. We feel that when it comes to diet and exercise it is particularly important to target mothers, as the women in the

community seemed to lead the most less active lifestyles and they are also responsible for the diet of the children and the men.

- Women should also be **engaged in conversation about the benefits of breast feeding**, highlighting that it is cheaper and healthier for children. The conversation should serve to inform rather than pressurise, and address Gypsy and Traveller women's main problems with the idea of breast feeding – privacy. It is important to tap into women's fears around child health, for example issues of cleanliness and risk of disease. In addition, we suggest offering free breast pumps (and demonstrations of how to use them) to pregnant women from the Gypsy and Traveller communities if they decide to try breast feeding.
- Men should be the focus of measures to **communicate the harmful effects of drinking excessively** and to remove some of the myths around alcohol (such as that some drinks are better for you than others). Men, unlike women, seem to be reluctant to talk about their health with other men, and peer-to-peer discussion may not be useful on this subject matter – the PCT should look to engage men individually, perhaps through workplaces, pubs or on-site at weekends.
- For all members of the Gypsy and Travelling communities in Mid Essex, beliefs about the inability to treat conditions such as cancer prevail – if **good information could be circulated** within the Gypsy and Travelling communities about the availability of effective treatment if illness is identified early, this might make people more likely to visit their doctor and to seek treatment for symptoms. In addition, it is clear that negative stories travel and remain within communities for along time – for this reason there should be a constant stream of good information being fed into the community, particularly around the benefits of vaccinations and breast feeding.
- **Opportunistic testing and vaccinations** appear to have worked as interventions with other groups and in other locations. The opportunistic discussion of lifestyle issues and screening programmes should be undertaken by health professionals as often as possible. In addition, visits should be used to raise awareness of smoking cessation and other health-related services. Visits from health professionals would be extremely beneficial to provide **spontaneous health-checks for any person living or visiting on-site**. Ideally they would travel in a mobile unit where privacy can be provided and it is easy for people to drop in when they are present on site. Men, who do not tend to go to the doctors until they reach crisis stage, would be the ideal focus of a general check-up including things like blood pressure testing.

Throughout this report we have highlighted the importance of pride and independence to the Gypsy and Travelling individuals and families we spoke to. Because of this it is extremely important that lifestyle messages are conveyed in a positive way, where possible emphasising the benefits of some behaviours rather than the negative consequences of other behaviours. This might prove particularly challenging when trying to communicate on some issues, such as smoking when pregnant.

6.1.2 Community incentivisation

Because the main lifestyle issues raised in the research are common across whole families and communities, it might be appropriate to consider **community incentivisation schemes which would capitalise on the close-knit nature of Gypsy and Travelling communities' ability to apply peer pressure to achieve a goal**. Some ideas for incentives to, for example, stop smoking or to lose weight might include:

- Financial incentives on an individual or community level
- Vouchers (the benefit over cash being to limit the possible spending to 'healthy' goods)
- Provision of a playground (with the added benefit of providing more safe space for mothers and children outdoors).
- Provision of other outdoor space which is safe for mothers and children, and which could be used for numerous activities such as gardening or exercise gardening/growing vegetables.

Whilst community incentivisation schemes can be extremely beneficial, there are a number of risks associated with such a programme, for example, that men might not be reached as they are not on-site to take part, and the incentive is competing with other social factors around the behaviours which might be the subject of the intervention. In addition, the negative aspects of peer pressure (such as isolation from the community if a person fails to conform) and ethical issues around providing schemes on some sites, or to some families, and not others should be considered.

6.1.3 Encouraging medical knowledge within the communities

Ideally it would be good to see more Gypsy and Traveller women and men undergo medical training to become nurses, doctors and other medical professionals. Current levels of education, and the qualifications achieved, amongst those of high-school age in the Gypsy and Traveller communities in Mid Essex don't appear to be conducive to this. However, with

education seemingly increasing in importance to the Gypsies and Travellers we spoke to, it may be that in a few years time the level of qualification needed to enter these sorts of courses will be more common.

There are opportunities which could be taken up by Gypsies and Travellers in Mid Essex, which would embed some knowledge within the community around medical responses and the services available to people generally. For example, the Health Trainers programme would help to get health-related knowledge onto sites and might lead to an improvement in the appropriateness of service access, as well as pushing people to visit their GP before it is 'too late'.

In addition, we feel strongly that first aid courses should be provided free of charge to Gypsies and Travellers who live on sites, which would be beneficial in recognising when something is wrong and medical help should be obtained, raising basic awareness of their own bodies and health matters, providing basic aid whilst waiting for an ambulance to arrive, and enhance the appropriate use of services generally. Courses should be delivered separately to men and women, and presented in slightly different ways to encourage people to attend:

- Promoting courses for women should focus around caring for the family, particularly the children, and would be particularly beneficial as women spend most of their time on-site and can respond quickly if something happens.
- Promoting courses for men should focus on the workplace and 'health and safety', using men's fear of injury and inability to work if they have an accident to convince them to take part.

It is important that the interventions developed empower individuals and communities to be independent, look after themselves, and use and request the services that they need and are entitled to. Encouraging the acquisition of medical knowledge within communities might serve this purpose well, allowing people to gain confidence in talking about health matters, and making the consideration of health part of day-to-day life. It would be crucial to make sure that refresher courses are provided and that new information to first aiders is passed on verbally, to ensure that good messages are circulating within the community.

6.2 Improving access to services

Most of the people we spoke with were registered with a GP, and many had had a GP for a number of years. It was clear that amongst those who lived on sites semi-permanently (who

appear to be most of the Gypsies and Travellers in Mid Essex) there were few problems with access to GPs or emergency services, and most were happy with the services they received (except for appointment systems and waiting times, problems also identified by the general population across other research). (The main issue in terms of access to services appears to be the time it took people to access them – waiting until the last possible moment to seek medical attention, often resulting in conditions so severe that it was necessary to go to Accident and Emergency.) For those who do not tend to live on sites and travel more, registration with a GP might be more difficult, and finding out about the services available might also be more difficult – intermediaries will be very important to these groups and we discuss their role below.

6.2.1 Medical advice and information

None of the Gypsies and Travellers we spoke to had heard of NHS Direct prior to meeting with us and they broadly thought that it was an excellent idea, and that they would use it now that they new about it. Some said that it might be a first port of call for them before going to the GP or Accident and Emergency. It is clear from this that **NHS Direct must be advertised more widely amongst Gypsies and Travellers** – whilst verbal spreading for information (especially attached to people's experiences of using NHS Direct) would be the most effective in terms of raising awareness, it might be useful to consider other measures such as a simple card with NHS Direct's contact details on it.

An extension of this method to other services might be helpful for Gypsies and Travellers in finding dentists, opticians and other healthcare providers. Whilst NHS Choices is out of the question for use by Gypsy and Traveller communities currently as a result of most not having access to the internet and poor literacy levels, it is also questionable the extent to which Gypsies and Travellers would want to choose between different healthcare providers. For many families, a lack of transport (especially for women in the daytime) means that it is likely that they would prefer to go to the nearest available healthcare provider. Therefore, **a simple document with the names of the services and their telephone numbers** should be provided. It was also suggested that simple pictures might help to identify what service different numbers refer to where literacy is an issue.

It would also be beneficial to Gypsies and Travellers, particularly to carers of elderly and disabled family members and neighbours, to be **informed of the benefits that they are entitled to**. Whilst most see caring as a family matter and a duty, and may not wish to claim the benefits available to them, there was also the suggestion that they might welcome some of the help available for the adaption of homes and the purchase of equipment which helps to

make caring – and the lives for those cared for – more comfortable. Again, the most logical channel for spreading knowledge on the entitlements available is the health worker or workers which frequent Gypsy and Traveller sites and take the opportunity to mention it to people if it looks like they might be in need. For this to be useful, however, there would need to be someone who could help them to fill in the complicated forms which are often needed to apply for these benefits.

6.2.2 Portable health records

It has been suggested by many sources that portable health records would be useful for the Gypsy and Travelling communities. This would be beyond the ‘Yellow Book’ currently in use as it would contain all of the health information in existence about a person and be completed by a medical professional. However, whilst the response to such an initiative from the people we spoke to was positive, there was not huge enthusiasm for the scheme. Many people spend most of their time on one site in Mid Essex and go to one GP only. The scheme might better suit those populations which travel more frequently and are not registered with a GP.

The practicality of this, however, is questionable. It is possible that GPs could be asked to print off the health records of Gypsies and Travellers if they request it, which they could then carry with them. Another option would be a card with a computer chip or a USB onto which GPs could record information when they are visited by a Gypsy or Traveller. However, this would require that people identify themselves as Gypsies or Travellers when they register with a GP (which many are reluctant to do for fear of discrimination) and that they do not lose the portable record or forget it when they visit the doctor. This, however, might be quite scary for people who do not have a great deal to do with computer technology and who would therefore be unable to access the information themselves. Both of these options would place an added burden on GPs who already consider that they do not have the time to spend on additional issues within appointment slots. The population of Gypsies and Travellers who do not live at least semi-permanently do not appear to make up many in terms of the Gypsy and Traveller population in Mid Essex as a whole, and they have proven extremely hard to access and keep track of – therefore, getting people to sign up to a scheme might be difficult.

Considering the current situation of the Gypsy and Traveller population in Mid Essex we feel that a scheme such as providing portable health records might not be cost effective or have much of an impact on Gypsies and Traveller’s access to local health services.

6.2.3 Appointment reminders

It was felt amongst participants that reminders for appointments would be extremely useful. Whilst some surgeries already do this, they do so by text message, and the participants felt that a phone call might be more useful for reminding them about appointments. However, unless doctors surgeries are aware that their patients are Gypsies or Travellers, it might be difficult for them to provide this service to them exclusively. Perhaps GP's surgeries might be encouraged to ask patients to state a preference for reminders at registration or when people attend an appointment.

6.2.4 The role of intermediaries

It has been implied throughout this chapter that intermediaries will be crucial in spreading the messages and implementing the interventions we have been discussing, and felt that it would be appropriate for a more detailed discussion of their role to take place here. The intermediaries which we have in mind as 'frontline' in the promotion of healthy lifestyles and health services to Gypsies and Travellers in Mid Essex are health visitors, health project workers from the PCT and Local Authority Site Managers. Health visitors have a very specific role in their interaction with communities (mothers and young children), and for this reason the gaps need to be filled in by others working with the Gypsy and Traveller communities in Mid Essex.

There is a need for **collaboration and joint working between health project workers from the PCT and Local Authority Site Managers** to make sure that good information is circulating within communities and that outreach is effective. Where site managers will enable the spread of some information on Local Authority sites, health project workers from the PCT might focus on private sites to make sure that they are receiving the same level of service. It is crucial that site managers and health workers from the PCT build up the trust of the communities they work with and get to know as many people in those communities as possible so that health-related problems can be identified before they become too serious and an intervention can take place. They are also a crucial point of contact for Gypsies and Travellers who should feel comfortable in approaching them for advice and information.

The PCT also needs to **develop its relationship with Gypsy Liaison Officers based at the County Council if it wants to reach temporary visitors to unauthorised or roadside encampments**, and either pass information to these individuals about initiatives and service provision or receive details of the whereabouts of new arrivals so that the health workers from the PCT can approach them with information independently.

Schools might also be viewed as intermediaries. In particular **primary schools might be a useful way of reaching Gypsies and Travellers with health-related information as most**

Gypsy and Traveller children attend at least until the end of primary school. Whilst it might not be appropriate to begin education about sexual health at this age, informing students about local services and healthy lifestyles is something which might get passed back to families at home and shape attitudes which children retain in the future. However, it is unclear how schools would identify Gypsy and Traveller pupils, and whether in the school environment it would be appropriate to target interventions at only a small number of children –health education is something which schools should (and probably already do) provide to all of their students.

6.3 Structural changes needed to promote healthy lifestyles and good access to services

The interventions which have been discussed above are things which Mid Essex PCT can take a lead on and implement, if they wish to do so, with little support needed from other local agencies. They tend to be interventions targeting specific behaviours and specific services, and involve informing and encouraging the target population to take responsibility for their own health and the health of their families. However, there are a number of issues which came out of the research, particularly around environment and living conditions which have a huge impact upon the health and wellbeing of Gypsies and Travellers, and which to change would require structural changes involving joint working between a range of agencies from across the Mid Essex area.

6.3.1 Improving access for women and children

It was very apparent from the work we did, particularly on sites (both Local Authority and privately owned) that **women and children in particular were trapped on small plots**, with little means of getting off the site and accessing the wider community. Some of the reasons for this were:

- Transport – public transport tended to not come within a reasonable distance of most sites, which were often miles away from health services, shops and other amenities
- Safe space – there were many safety issues with vehicles on sites, and routes off sites were often not felt to be safe as they lacked pavements for people to walk on
- Nowhere to play – linking to the safety and space issues above, there is little common space on sites, and nowhere for children to play safely. As well as compromising safety this also contributes to a less active lifestyle for women and children.

To address some of these issues would need the cooperation of agencies involved in land allocation, responsible for roads and those responsible for bus routes in Mid Essex.

6.3.2 Provision by local agencies

From the literature review and from other work done around site provision and land allocation, it seems that Gypsies and Travellers experience a much better lifestyle and access to services when localities have the **political will and capacity to provide adequate land for site provision and to approve planning permission for privately owned land.**

For this reason, Gypsies and Travellers in Mid Essex appear to fair better than Gypsies and Travellers in other localities, where less land is available for pitches and evictions are more commonplace. The agencies operating in Mid Essex should be praised for their hard work in the Mid Essex area, and should endeavour to continue providing services and improving services for Gypsies and Travellers.

A measure which seems to work particularly well is **involving Gypsies and Travellers in the management of sites**, which empowers the communities to take control over their own lives and to argue for the services they need. Having community members in leadership positions with contacts in local agencies can only be beneficial in spreading good messages around health and available services. A number of people raised the design of Local Authority sites as an issue, feeling that plots often lacked privacy and were not very attractive. There have been a number of initiatives to design sites more effectively (such as the Salford University Initiative) and these sorts of schemes might be taken into consideration if redesigning or allocating new sites in the Mid Essex area. Most importantly, the communities themselves should be consulted on these matters.

Where sites are privately owned a community representative might be invited to shape the services in their area by speaking with PCT and Local Authority representatives on a regular basis or when a decision needs to be made on a local matter. This will ensure that privately owned sites are getting adequate consideration in the design and provision of local services.

Appendices

7. Appendices

7.1 Bibliography

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7.2 Stakeholder interview discussion guide

Mid Essex PCT – Gypsies and Travellers Stakeholder interview discussion guide

Objectives of the interviews:

- Provide an overview of the current health behaviours of Gypsy and Travelling communities living in Mid-Essex;
- Explore the experiences of Gypsy and Traveller communities who are accessing and/or using local healthcare services;
- Explore the values, barriers, expectations, incentives, dis-benefits and benefits of local healthcare services from the Gypsy and Travelling community point of view
- Explore the experiences and views of healthcare professionals involved in the delivery of services to Gypsy and Traveller communities living in Mid Essex;
- To understand more about past and current initiatives / services and what has/hasn't worked and establish how health improvement services could be better targeted

Description	Comments	Time (mins)
1. Introduction and warm-up	Warm up – introduce the project, explain ground rules	5 mins
2. Involvement with Gypsies/Travellers	Get information about interviewees job role and their experiences/involvement in working with Gypsies/Travellers	10 mins
3. Key issues/ health issues with Gypsies/Travellers	Grounding the research in the local context. Understanding the wider health, cultural challenges/issues.	10 mins
4. Barriers to accessing services, previous health initiatives	What has happened already? What's worked, what hasn't? Indicators of success. Motivators, barriers facilitators	15 mins
5. Future initiatives, communicating messages	What would you like to see happen in the future? What challenges do you foresee? How to best target messages.	15 mins
6. Wrap up	Wrap up	5 mins

Description	Comments	Time (mins)
<p>1. Introduction and warm-up</p> <p>Thank participants for agreeing to take part – mention that the discussion should last up to one hour</p> <p>Stress there are no right or wrong answers – we are just interested in finding out their views and opinions. Reiterate that there will be a chance for them to shape the agenda of the discussion</p> <p>Reassure participants of confidentiality – we will not attribute comments to them</p> <p>Objective of the research is to gain a deeper understanding of Gypsy and Traveller communities, specifically their health-related behaviour, in Mid Essex</p> <p>Permission to record – for analysis purposes only</p>	<p>Warm up - covers general rules, insofar as there are any, and the information we are required to tell participants.</p> <p>Informs about the objectives of the research</p>	<p>5 mins</p>
<p>2. Involvement with Gypsies/Travellers</p> <p>Could you explain to me what your role is with regard to Gypsies and Travellers?</p> <p>Could you tell me about your understanding/knowledge of Gypsy and Traveller communities IF NECESSARY PROBE ON Experiences</p> <p>Explain to me what you know about Gypsy and Traveller groups/sites. IF NECESSARY PROBE ON differences between different types of sites</p> <ul style="list-style-type: none"> - Authorised <ul style="list-style-type: none"> - Local authority owned - Privately owned - Unauthorised <ul style="list-style-type: none"> - Encampment (do not own the land they use e.g. roadside, playing fields etc) - Developments (own land but without planning permission) <p>Or Ethnic groups</p> <p>What are the general priorities for Gypsies and Travellers? IF NECESSARY PROMPT ON policy, priorities from the G&T community perspective</p>		<p>10 mins</p>
<p>3. Key issues/ health issues with Gypsies/Travellers</p> <p>What are the key health issues for G&T in Mid Essex generally? PROBE:</p> <ul style="list-style-type: none"> ▪ What are the health priorities? ▪ Are there any challenges to G&T? <p>Are health behaviours of Gypsies and Travellers any different from other communities you deal with? How?</p>		<p>10 mins</p>

Description	Comments	Time (mins)
<p>IF NECESSARY, PROMPT ON: Diet/obesity, exercise, smoking, alcohol, sexual health, accessing health services such as GPs/A&E/dentists, children's health, immunisations, screenings</p> <p>Are there any differences between different types of sites in terms of:</p> <ul style="list-style-type: none"> - the health-related behaviours of the community? - their health needs? - Provision of services 		
<p>4. Barriers to accessing services, previous health initiatives</p> <p>Is it important to provide specific/tailored services to these communities? Why/why not?</p> <p>Are available services well used? If not, why is that? What do current services/initiatives 'look like'? Who are they targeting, how are they advertised etc.</p> <p>Is there anything which prevents or discourages Gypsies and Travellers from using local health services?</p> <p>Is there anything which would encourage greater use of local health services among Gypsies and Travellers?</p> <p>Do you know of any initiatives/health interventions that have been used to improve G&T access to/use of health services in Mid Essex? PROBE:</p> <ul style="list-style-type: none"> ▪ What initiatives have there been? ▪ What has/hasn't worked in the past? ▪ What are some of the key barriers/facilitators? ▪ Why have initiatives failed/been successful in the past? <p>How are services best delivered/offered to these communities? PROMPT ON mobile or stationary services</p> <p>What about NHS direct? Do you know if these communities are aware of this service? Do they use it? Why/why not? Do you think it is an appropriate way to provide health advice/information to these communities?</p> <p>And how about the NHS Choices website? Do you think this would be useful? IF NECESSARY PROMPT ON: condition management, improving lifestyle, info on treatment and local services.</p>		15 mins
<p>5. Future initiatives, communicating messages</p> <p>What would you want to see changed with how health services are provided? How/why?</p> <p>What do you feel are the best ways of communicating messages to the target population? PROBE:</p> <ul style="list-style-type: none"> ▪ Which channels work best? ▪ What's worked in the past? 		15 mins

Description	Comments	Time (mins)
<ul style="list-style-type: none"> ▪ What channels are available? Local media, local papers, newsletters, charities, community groups? <p>What services/initiatives would you like to see available in the future? PROBE:</p> <ul style="list-style-type: none"> - Do they exist already? - What do you think would be most effective? - To what extent do you think the G&T population want to engage with local health services? <p>How do you think our findings should be communicated to these groups?</p> <p>What would you want to see come out of this research? Why?</p> <p>Are there other people who you think we should be speaking to as part of this research?</p>		
<p>7. Wrap up</p> <p>What is the one message we should take back? What one thing would you like to see changed?</p> <p>Are there any issues we haven't discussed that you'd like to mention?</p> <p>Mention next steps with Steering Group if relevant</p> <p>THANK AND CLOSE</p>		5 mins

7.3 Depth interview discussion guide

Mid Essex PCT – Gypsies and Travellers Depth interview discussion guide

Objectives of the interviews:

- Explore current health issues and beliefs amongst Gypsy and Travelling communities living in Mid-Essex
- Explore the experiences of Gypsy and Traveller communities accessing and/or using local healthcare services
- Understand current barriers to accessing health information and services for Gypsy and Travelling communities
- Explore possible enablers to improve Gypsy and Travelling communities access to health information and services

Moderator notes:

A comprehensive literature review has been undertaken by this project – please read thoroughly and discuss with a core team member before your interviews.

Many health concerns for Gypsy and Traveller communities may relate to environmental health issues on their site: try to note down any observations you have about the condition of the site you visit and its implications for health.

Traditional gender roles endure in these communities and this is likely to have an impact on health and the discussion of health-related matters. For this reason we are gender-matching moderators. Be careful about how you approach community members of the opposite sex in general whilst you are visiting a site, and avoid discussing personal health issues if there is anyone of the opposite sex within earshot of you and your respondent.

Low levels of literacy are a big issue in this community – try to avoid complex terminology as it may alienate your respondents. If possible try not to have the guide in front of you at all; using a digi is also probably better than writing notes in this sense.

Description	Comments	Time (mins)
<p>1. Introduction and warm-up</p> <p>Thank participants for agreeing to take part – mention that the discussion should last about 45 minutes</p> <p>Stress that there are no right or wrong answers – we are just interested in finding out their views and opinions. Reiterate that there will be a chance for them to shape the agenda of the discussion</p> <p>Reassure participants of confidentiality – we will not attribute comments to them</p> <p>Objective of the research is to gain a deeper understanding of Gypsy and Traveller communities’ health concerns and service needs, and how to improve service and information provision.</p> <p>Permission to take notes/record – for analysis purposes only</p> <p>Assure participants that we will pay incentive of £20 at the end of the interview.</p> <p>Warm up questions</p> <ul style="list-style-type: none"> - How long have you lived here (on this site/in this house etc.)? - Do you like living here? - Have you moved around much? / Do you live here permanently? 	<p>Time keeping and formal schedules may be an issue – try to arrive early and be prepared for delays and changes of plan. Go with the flow!</p> <p>Privacy is a real concern– reassure about confidentiality and participants rights to answer only what they wish. You may not be able to take notes or record. You should be flexible and prepared to take notes following the interview.</p>	5 mins
<p>2. Current health issues and beliefs about health</p> <p>I’d like to talk today about health and wellbeing.</p> <p>When you think about being healthy, what does that mean for you?</p> <p>Is it something you think about much? For yourself? Your family/friends? Why/not?</p>	<p>See if good health services are mentioned unprompted or if it is more about lifestyle, being outside, money, living conditions/the local area</p> <p>Beliefs about privacy may make it difficult to discuss personal health issues. If so, try projective techniques, asking about other people. On the other hand, beliefs about individual autonomy may mean that interviewees are</p>	15 mins

Description	Comments	Time (mins)
<p>How much do you think about it, compared to other things in your life, such as education, employment, happiness, family?</p> <p>How do you feel about your own/your family's health currently? E.g. fitness, weight, medical conditions, eyes/teeth etc. PROBE:</p> <ul style="list-style-type: none"> - Would you rate it as generally good/bad? - Why do you say that? - Would you mind telling me what aspects of your health give you cause for concern? <p>What causes these health problems that you mentioned? How do you know this/where did you find out about this?</p> <p>How about how you feel in yourself – do you (or people you know) ever have problems with stress, worries or feeling down? PROBE:</p> <ul style="list-style-type: none"> - Why does this happen? - Who does it tend to happen to? - What can/should be done about it? <p>How do you keep yourself healthy? What things are most important in helping you be healthy? PROBE:</p> <ul style="list-style-type: none"> - In what ways can you improve/damage your health? - Why do you say that? - Can you do anything to prevent major health problems? <p>Do people have the same health issues or is it different depending on where people live, e.g. on other sites/in housing/on the road?</p> <p>Do you/your family/someone you know care for someone who is ill, elderly or has a disability? PROBE:</p> <ul style="list-style-type: none"> - Who? For what conditions? 	<p>uncomfortable talking about other people!</p> <p>Be careful how you address major health problems such as cancer – these are often referred to using euphemisms such as 'the bad thing' – it may make people uncomfortable discussing them.</p> <p>Try to show respondents that you are open minded about the causes and treatments of illness and disease, don't assume they will be the same as your own but beware of being patronising!</p> <p>Information channels are key for us to feed back to the NHS – literature suggests lots of passing down of information between generations and that official information is not getting through due to isolation and low literacy rates.</p> <p>Try to address mental health issues sensitively – don't use the words 'mental', 'mental illness', 'mental problems', 'mad' or 'crazy' – use words like 'worry' or 'anxiety' instead.</p> <p>Listen out for/probe on things like alcohol, smoking, diet which are big issues in this group according to the NHS</p> <p>The literature review revealed ideas about fatalism –if you are meant to be sick you will get sick, there isn't much you can do about it. Also, ill health seems to be an accepted part of getting older.</p> <p>There is a suggestion in the literature review that mobility affects health – listen out for differences, e.g. travelling is good for your health, physical health problems restrict the ability to travel etc.</p> <p>Lit review suggests that there are many more carers than</p>	

Description	Comments	Time (mins)
<ul style="list-style-type: none"> - How is this going? - Do they need any help? - Do they get this help? From whom? <p>How do you feel about immunisations – for yourself/your children/your family? PROBE:</p> <ul style="list-style-type: none"> - Do you think that they are healthy? - Have you/your children/your family had any immunisations? - How can we help people get immunisations? 	<p>average and that there is a preference for being cared for at home by family rather than in an institution/hospital. Try to probe on this if it isn't feeling too sensitive.</p>	
<p>3. Access to health information and services</p> <p>How do you treat [THE HEALTH PROBLEM MENTIONED EARLIER]? PROBE:</p> <ul style="list-style-type: none"> - At what point would you seek treatment rather than dealing with it yourself? - Who would you go to for treatment? (PROBE: doctor, hospital, health visitor, lay people in the community, etc.) - Why do you choose that particular place/person? - What would they do about it? <p>Does anyone come out to you on site for health problems? Should they? Why/not? What do you think of the treatments you have received? PROBE:</p> <ul style="list-style-type: none"> - Actual treatment? - Staff attitude? - Facilities available? - Ease of access? <p>How easy/difficult do you find it to access NHS medical services (e.g. GPs, health visitors, hospitals, emergency care etc. – SEE COMMENTS)? PROBE:</p> <ul style="list-style-type: none"> - Why do you say that? - What makes it easy/difficult? 	<p>REPEAT THIS IF THERE ARE MULTIPLE HEALTH CONCERNS MENTIONED – look out for different ways in which different illnesses are dealt with.</p> <p>Listen out for what services are being accessed and beliefs about illness and treatment. The lit review suggests a lot of stoicism and late treatment seeking, especially amongst men.</p> <p>Try to allow for spontaneous mention of what services and information sources the respondent is aware of before probing on specifics.</p> <p>Many sources mention problems with receptionists, lack of permanent addresses to register with, and high levels of A&E use. Listen out for these.</p>	15 mins

Description	Comments	Time (mins)
<ul style="list-style-type: none"> - Is this different from one site to another? - Are some services easier to access than others? - Do you want to access any services that you can't? Which ones? <p>How about getting information about health issues and services? PROBE:</p> <ul style="list-style-type: none"> - Do you have enough information about where you can get help for different types of medical issues? - Where/who do you get this information from? Where/who would you go to if you wanted information? - What format should it be in (written, telephone, face to face.....) - Do you need any health services or medical information or is it not important? - <u>NHS Direct (phonenumber/website), NHS Choices (website) - do people know about this? Do they use it? Do they think it is a good idea? How could this be improved?</u> <p>How about things like reminders for appointments? Do you get these? Do you want them? PROBE: written, phonecall, text message etc.</p>	<p>Probe on non-treatment services too such as screening, antenatal care, immunisations, well woman/man clinics as these reported have very low take-up. Also dentistry, opticians, pharmacies, emergency service access – it can be difficult to get ambulances to site etc.</p> <p>Remember that many respondents may have limited literacy. Try to be sensitive when raising questions about information access.</p> <p>Some areas provide telephone contacts for services or an information sheet for new residents on a site, listen out for these. Also probe for NHS direct phone line and websites.</p>	
<p>4. Barriers and enablers for access to services and information</p> <p>Is there anything which prevents or discourages you (your family/friends/community) from using local health services?</p> <p>Is there anything which would encourage you (your family/friends/community) to make greater use of local health services?</p> <p>Are you aware of any initiatives to make it easier for you to access services? PROBE:</p> <ul style="list-style-type: none"> - Which ones? - Who runs them? - How do you rate them? 	<p>Whilst research suggests low take-up amongst travelling communities of health services, it should not be taken for granted that they actually feel a need for these services – it is possible that they have their own ways of coping with illness that do not need to involve health professionals; assess how important your respondents think NHS intervention in their lives actually is compared to other issues such as the issue of site access, education, jobs etc.</p>	10 mins

Description	Comments	Time (mins)
<p>- Which sites are these aimed at? Is this appropriate?</p> <p>Do you think it would be useful/important to provide NHS services specifically tailored to Gypsies/Travellers/Roma or are you happy to access the same services as other residents of the local area?</p> <p>IF SAID TAILORED SERVICES FOR TRAVELLING COMMUNITIES: Can you give me some examples of specific services that you might need?</p> <p>Are there things that you think need to happen with NHS staff to help them offer a better medical service to you/your family/friends/community?</p> <p>PROBE:</p> <ul style="list-style-type: none"> - Such as? - How would this help? 	<p>These are examples of good practice which came up in the literature review, such as health visitors coming to sites, health education sessions on site, training of Travellers in basic healthcare and first aid, phone reminder services, patient record cards, drop in clinics, information packs on services for new residents. If they are stuck for ideas you could test these out.</p> <p>Literacy awareness and race issues training for GPs/nurses, enforcement of registration rights for all members of the community with GP surgeries, having same gender GPs are some ideas which came out of the lit review.</p>	
<p>5. Wrap up</p> <p>What is the one message we should take back?</p> <p>What one thing would you like to see changed about the way the NHS works?</p> <p>Are there any issues we haven't discussed that you'd like to mention?</p> <p>MENTION NEXT STEPS IF RELEVANT</p> <p>THANK AND CLOSE</p>		5 mins