



Health and social care needs of Gypsies and Travellers in West Sussex

Report to NHS West Sussex and West Sussex County
Council

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Introduction

The Office for Public Management (OPM) was commissioned by NHS West Sussex and West Sussex County Council (WSCC) to conduct an assessment of the health and social care needs of Gypsies and Travellers in West Sussex. The aims of the project were to:

- Describe the Gypsy and Traveller population of West Sussex and their health and social care needs
- Use qualitative and quantitative information to evidence what existing services are and are not meeting these needs
- Identify any gaps in services
- Compare findings with national research and best practice
- Identify further opportunities for service improvement, e.g. partnership working, service access, etc.
- Identify key priorities for commissioners and other interested stakeholders
- Suggest indicators for monitoring progress towards addressing improvements and unmet needs
- Produce a report aimed at policy makers and commissioners, but easily understood by all key stakeholders.

The health and social care needs assessment for Gypsies and Travellers will form part of the overall Joint Strategic Needs Assessment being carried out by NHS West Sussex and WSCC, and will be used to inform future commissioning strategies and decisions.

Methodology

Overall approach

OPM's approach to this project was shaped by research into the social determinants of health and the historical, cultural and political context influencing Gypsies' and Travellers' lives. It was not our intention to produce an epidemiological study of Gypsies and Travellers in West Sussex, nor a report that examined health needs through health status and health care utilisation figures alone. Given the timescale and resources available for the project, we decided not to generate fresh quantitative data on Gypsies and Travellers in West Sussex. Rather, our aim was to examine existing quantitative data, and to use interviews with Gypsies and Travellers and with stakeholders to generate rich qualitative data, in order to gain valuable insights and understanding into the many complex and inter-linked issues affecting the health of Gypsies and Travellers in West Sussex, their access to and use of services, and their views of service gaps and potential improvements. OPM gained the evidence and information for this project in a number of stages, as explained below.

Desk research: document and literature review

The desk research was divided into two elements:

- a) Local and regional data
- b) National data, comparative data, case studies and good practice

A list of documents reviewed is provided in Appendix 1.

Local and regional data

Local and regional data were collected and analysed through a document review. A key aim was to collate demographic information about the composition, size and location of Gypsy and Traveller populations in West Sussex, so that these could be mapped against current services targeted at / working with people from Gypsy and Traveller communities. OPM worked with NHS West Sussex and West Sussex County Council to identify and review key local and regional documents. Further documents, including reports of previous relevant projects and events, were provided by Friends, Families and Travellers (FFT), and the Sussex Travellers Action Group (STAG). Information about authorised and unauthorised Gypsy and Traveller sites was obtained from a number of sources, including West Sussex County Council and the seven district and borough councils within West Sussex.

National and comparative data

OPM conducted a literature review to identify national and comparative data. We reviewed documents providing a national and/or best practice perspective on the health and social care needs of Gypsies and Travellers. An initial set of documents were provided by NHS

West Sussex, and supplemented through discussions with Zoe Matthews of FFT, an acknowledged national expert on Gypsies' and Travellers' health. Further documents were identified using a search of the King's Fund library database. The inclusion criteria were:

- That the document title included keywords: 'Gypsy' or 'Gypsies' or 'Traveller' or 'Travellers' AND 'health' or 'healthcare' or 'social care' or 'care' or 'needs' or 'needs assessment'
- That the document was published in the last ten years (2000 or later)
- That the document referred to Gypsies and Travellers in part of England, England or the UK

Selected documents were reviewed using a data extraction template.

Interviews with stakeholders

OPM conducted 11 semi-structured interviews by telephone with stakeholders, to provide a deeper understanding of the needs of Gypsies and Travellers in West Sussex, the issues they face in relation to health and social care services, barriers to access and gaps in services. Interviewees were selected on the basis of having direct experience and knowledge of working with Gypsy and Traveller communities in West Sussex, and to cover a range of services and professional backgrounds. The findings from the interviews were used to shape and scope the topic guides for the interviews with Gypsies and Travellers, and the issues discussed at the stakeholder workshop. Interviewees included: WSCC Travellers and Enforcement team, health visitors, an oral health promotion co-ordinator, a mental health community support worker; a representative from Sussex police, a representative from the adult and children learning department at WSCC, a WSCC customer focus appraisal adviser, and staff from third sector community organisations specialising in working with Gypsies and Travellers. The list of interviewees and the interview topic guide are given in Appendices 2 and 3.

In addition to these semi-structured interviews OPM also met with staff from FFT: Zoe Matthews, Health Improvement Manager and an acknowledged expert on the health and health needs of Gypsies and Travellers, and Avril Fuller, Social Care Outreach Worker, who has many years of experience working to support the Gypsy and Traveller community.

Interviews with Gypsies and Travellers

OPM conducted face-to-face interviews with Gypsies and Travellers, in order to deepen our understanding and insight into key factors affecting health, and perceptions and experiences of health and social care services. The aim was to gather high quality primary data on health and social care needs including health status and experiences, perceptions and attitudes to health, behaviours, use of health and other services, and perceptions of such services including perceived barriers to access.

For this part of the project, OPM worked in partnership with FFT, a national information, advice and advocacy organisation for Gypsies and Travellers, based in Sussex. FFT have many years' experience of working with Gypsies and Travellers in Sussex, and have

established relationships with many Gypsies and Travellers, including through their Sussex Traveller Health Project. FFT contributed to the topic guides and questions for the interviews, and used their established relationships and knowledge of the Gypsy and Traveller community to recruit interview participants and arrange interviews. This was especially valuable as the issue of trust is widely acknowledged as highly significant for both researchers and services seeking to work with the Gypsy and Traveller communities. Gypsies and Travellers are known to often be highly mistrustful of staff and organisations that they do not know, who just 'turn up' and ask them to take part in interviews, and who may also display cultural insensitivity.

Our initial intention was to conduct 10 face-to-face interviews and hold three discussion groups for up to 10 people each. We planned to run one of the discussion groups solely for men and with male facilitators, as previous research studies have found it particularly difficult to engage Gypsy and Traveller men in discussions about health issues. Our aim was to achieve participation overall from: men and women; people in different geographical areas / sites within West Sussex; Gypsies and Travellers who are housed, those using council sites, private sites, and those using unauthorised sites/roadside areas; and people from the different constituent groups within the West Sussex Gypsy and Traveller populations e.g. Irish Travellers, Roma people, England and Welsh Gypsies. The project did not aim to include New Travellers, or show, fairground or circus people.

In practice, recruitment for this part of the project was slower and more opportunistic than had been envisaged. Several people agreed to take part in interviews, but then withdrew at short notice – sometimes for health related reasons, such as a relative being admitted to hospital, or children being unwell. On some occasions, when an interview had been arranged but a person then withdrew, FFT and OPM staff approached other people living nearby (e.g. on the same site), who spontaneously agreed to take part in an interview. Some people were willing to be interviewed as part of a small group, but not on a one-to-one basis. In several cases, members of the same family chose to be interviewed together. As an incentive to take part, and to thank them for their time, each interviewee was remunerated with £20.

Interviewees were told that interviews could be given anonymously or using pseudonyms, to preserve confidentiality. When interviewees gave consent, interviews were recorded. If interviewees did not want them to be recorded, then notes were taken by the interviewer instead.

We did not run any discussion groups, but instead took a flexible and opportunistic approach to conducting interviews, and interviewed people individually and in small groups.

We interviewed 21 people:

- Six individual interviews
- Two interviews with two people together
- One interview with three people together
- Two interviews with four people together

All of the people we interviewed were either living in West Sussex, or had direct experience of using services in West Sussex. Some were staying at the transit site in Brighton at the time of the interview.

The gender breakdown of interviewees was:

- Four male
- 17 female

Not all interviewees disclosed their ages, but the age range of interviewees was from 12 to 60+.

- One of the interviewees was of Irish Traveller origin
- Two interviewees from the same family did not identify ethnically as Gypsies or Travellers, but had lived on sites for decades; one had previously travelled before moving to the site
- All the other interviewees identified as Gypsy, Romany Gypsy or English Gypsy

The accommodation situation of interviewees at the time of the interview was:

- Five in permanent housing
- One in temporary housing (social housing)
- 11 living on authorised local authority sites
- Four staying at Brighton transit site (travelling)

The location of where interviewees were living / staying at the time of the interview was:

- Nine in Burgess Hill
- Five in Brighton
- One in Haywards Heath
- Six in Chichester

We did not interview anyone living on a permanent authorised private site.

Interviews were semi-structured. The interview topic guide is given in Appendix 4.

Stakeholder workshop

A stakeholder workshop was held in July, at which our initial findings were presented and discussed. The aim of the workshop was to test our findings against stakeholders'

experiences, and to explore in more depth the difficulties and challenges in providing services that meet the health and social needs of Gypsies and Travellers in West Sussex, and possible new approaches and solutions. We invited many of the people who had taken part in the stakeholder telephone interviews, as well as others from across West Sussex who work with or have an interest in Gypsy and Traveller communities. The list of stakeholder workshop attendees is given in Appendix 5.

Because progress with recruiting Gypsies and Travellers to take part in face-to-face interviews had been slower than hoped, at the time of the stakeholder workshop, nine people had been interviewed, all of them women.

Gypsies and Travellers in England and the UK

This section provides an important backdrop to understanding the health and social care needs of Gypsies and Travellers, and the various complex factors which affect Gypsies' and Travellers' relationship with, and use of, health and care services. In particular, it is necessary to explain the historical and political context that has given rise to a strong degree of mutual suspicion and hostility between some Gypsies and Travellers and the settled community, and severe mistrust shown by many Gypsies and Travellers toward 'the authorities' in the form of the police, local councils, and other statutory public bodies, including health and social care services. This is described by Parry¹ whose research found that "prior experience and expectation of racism was closely associated with mistrust of non-Travellers in general that leads to defensive hostile behaviour and avoidance of unnecessary encounters with non-Travellers."

An understanding of the various kinds of accommodation in which Gypsies and Travellers live is important, as there are different health impacts associated with different accommodation types and travelling status.

Historical context

Gypsies and Travellers have lived and worked in the UK for over 500 years. Genetic and linguistic evidence shows that Romany people probably originated from the Indian subcontinent, migrating westwards sometime during or after the 11th century AD. The first Romany people are thought to have arrived in Britain during the 15th century AD.

There is a centuries long history of prejudice and ill-treatment of Gypsies and Travellers in Europe, including enslavement, enforced labour, forcible removal of children, expulsions and deportations, hangings, branding and disfigurement. In England in the 1500s, persecution of Romany people was enshrined in several laws. The Egyptians Act 1530 banned Romanies from entering the country, and required the expulsion of those already here within 16 days. The Egyptians Act 1554 required them to adopt a settled lifestyle, with failure to comply punishable by death. Although these laws were repealed in the late 18th century, prejudice against Gypsies and Travellers has remained deeply embedded in British society for centuries.

In the 19th century, legislation was passed preventing nomads from camping on the roadside. The Enclosure Act 1857 and Commons Act 1876 made it harder for Gypsies to camp on village greens. The 20th century saw more legislation affecting Gypsies and Travellers, adding further constraints to their ability to travel. The Caravan Sites and Controls of Development Act 1960 gave local authorities discretionary powers to provide sites for Gypsies and Travellers. It introduced a requirement for landowners to have a licence before they could allow a caravan site on their land. It also enabled district councils to make orders preventing caravans from being stationed on common land or town or village greens. The effect was to prevent Gypsies and Travellers from staying at the vast majority of their traditional stopping places.

¹ *The Health Status of Gypsies and Travellers in England*, report for Department of Health, Parry et al, University of Sheffield, October 2004

The Caravan Sites Act 1968 introduced an obligation on local authorities to provide caravan sites for Gypsies and Travellers, if there was a demonstrated need. However, many local authorities were resistant, and claimed that there were few or no Gypsies within their areas. As a result, not enough pitches were developed and provided. Those Gypsies and Travellers who were granted a pitch then risked losing it if they went travelling, so that Gypsies' and Travellers' ability to travel was severely curtailed. Furthermore, those council sites that were developed under this legislation were often on poorly located sites, often near to sewage or refuse disposal sites, with poor facilities, amenities and transport links.

Traditionally, the travelling patterns and employment of many Gypsies and Travellers were inextricably linked. Gypsies and Travellers followed a largely agricultural cycle of working and travelling; travel would be based on working on the land, with many families following the same routes and visiting the same farms each year, providing labour for activities such as crop picking. Farmers would have a long-standing relationship with particular Gypsy and Traveller families, and expect them to arrive at the same time in the agricultural cycle each year. However, increasing legal restrictions on Gypsies' and Travellers' ability to travel and camp in the traditional way, coupled with mechanisation in agriculture and alternative sources of cheap labour such as migrant workers from other parts of Europe, have all made this way of life much more difficult for most Gypsies and Travellers to maintain. Breeding and trading horses was also a major source of employment amongst Gypsies and Travellers. Nowadays much agricultural employment has been replaced amongst Gypsy and Traveller men by work such as market trading, scrap metal dealing, gardening, building, laying tarmac, buying and selling electrical goods, and used car trading. Gypsies and Travellers tend to be self-employed or work for family members.

Although the majority of Gypsy and Traveller women do not work, the EHRC report² says that anecdotally and through Gypsy and Traveller accommodation needs assessments, evidence is emerging that married women with school-aged children are starting to enter employment in low but increasing numbers, often in unskilled jobs such as cleaning. The report also cites increasing interest amongst younger Gypsy and Traveller women in entering health and beauty-related occupations where they could work on a self-employed basis, despite some cultural resistance from older relatives.

The CRE³ in 2004 reported a lack of systematic data on Gypsy and Traveller employment, but cited anecdotal evidence indicating high levels of unemployment. The EHRC report⁴ gives an overview of the barriers to mainstream employment faced by many Gypsies and Travellers, including racism, lack of a settled address, lack of bank accounts, poor literacy, and low skill levels and qualifications.

Recent policy and legislation

The Criminal Justice and Public Order Act 1994 abolished the duty of local authorities to provide council pitches for Gypsies and Travellers, and introduced new police powers to move Gypsies and Travellers on, even when they have nowhere to go to. The Act created

² *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

³ *Gypsy and Traveller Strategy for England and Wales*, Commission for Racial Equality, 2004

⁴ *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

several new trespass offences, although guidance requires the welfare needs - including health needs - of trespassers to be considered. A House of Commons Library briefing⁵ says that "it is probably not compliant with the European Convention on Human Rights to evict trespassers who have nowhere to go." Financial support from central government to local authorities for site development was withdrawn. Government policy at that time was that Gypsies and Travellers should buy their own land and apply for planning permission to occupy it. However, in practice, most people who tried to do this found it extremely difficult to gain planning permission.

Labour government policy

In 2004, the Labour government issued *Guidance on Managing Unauthorised Camping*. This recommended that councils develop local policies on unauthorised camping, and should aim to balance the rights and needs of resident communities with those of Gypsies and Travellers. It also said councils should work with the police and other partners to address social exclusion amongst Gypsy and Traveller communities. The Guidance told local authorities to review the provision of Gypsy and Traveller sites and involve Gypsies and Travellers in site planning and design. It said local authorities should consider the provision of authorised sites as part of the strategy for addressing unauthorised encampments.

The Housing Act 2004 required councils to assess the accommodation needs of Gypsies and Travellers and develop a strategy setting out how any identified need would be met. In 2006, a Planning Policy Statement⁶ made clear that the government expected Regional Spatial Strategies and Local Development Frameworks to aim to achieve a mix of housing, and these should specifically take into account the needs of Gypsies and Travellers. *Planning for Gypsy and Traveller Caravan Sites, circular 01/06* set out in more detail how the planning system was meant to ensure adequate site provision. The Labour government set targets for the number of new Gypsies and Travellers sites that local councils should develop, and provided £150m over five years through the Gypsy and Traveller Site Grant, to fund their development.

Coalition government policy

Since the May 2010 general election, national policy regarding Gypsies and Travellers has changed again. In May 2010, the incoming government scrapped the Gypsy and Traveller Site Grant, including the current financial year's allocation of £30m, thus 'freezing' planned site developments across the country. Regional Spatial Strategies were abolished in July 2010.

In August 2010, the government announced it was scrapping the previous government's planning targets for numbers of authorised Gypsy and Traveller sites in each area, and instead will introduce financial incentives for local authorities to develop more authorised

⁵ *Gypsies and Travellers: Camp sites and trespass*, House of Commons Library briefing note SN/SC/1127, August 2010

⁶ *Planning Policy Statement 3: Housing*, Dept for Communities and Local Government, 2006

sites⁷. Gypsy and Traveller sites will be included in the New Homes Bonus Scheme, under which councils will be given financial rewards for allowing new homes to be built in their areas. The timing for this to come into effect has not yet been announced, as the New Homes Bonus Scheme will be subject to a public consultation later in 2010. With the scrapping of planning targets, it will be up to each council to decide how many new Gypsy and Traveller sites or pitches to develop.

Following a 2004 ruling of the European Court of Human Rights, the Housing and Regeneration Act 2008 gives Gypsies and Travellers living on sites the same rights as others living in mobile home parks; however, the relevant section of the Act has not yet come into force. Although the coalition government has stated its intention to proceed, it remains unclear when it will be brought into effect. The government has also announced its intention to introduce stronger enforcement powers for councils in relation to unauthorised encampments.

The implications of these recent policy changes, and their impact on the health and health needs of Gypsies and Travellers in West Sussex cannot yet be known. However, despite the previous government's attempts to take a nationwide strategic approach to increasing authorised site provision for Gypsies and Travellers, there remains serious under-provision. A Department for Communities and Local Government progress report on Gypsy and Traveller policy in July 2009⁸ said: "the current position on site delivery remains unsatisfactory. It is clear that local authorities need to increase the pace at which suitable locations are identified that can be used as Gypsy and Traveller sites". The various health issues associated with poor quality sites, with enforced travelling due to a lack of sites, and with living in bricks and mortar housing are discussed in the section on the Health and Health Needs of Gypsies and Travellers, below. For West Sussex, much depends on how the county council and district and borough councils respond to the changed policy environment, and the approach they decide to take to improving provision of accommodation for Gypsies and Travellers in various forms, including transit sites, improvements to existing authorised council sites, the development of new authorised council sites, and the development of authorised private sites. Inevitably, those decisions will impact on the health and needs of Gypsies and Travellers in the county.

Numbers of Gypsies and Travellers in England

There are no accurate data available on the number of Gypsies and Travellers in England or the UK. There has been no systematic ethnic monitoring of Gypsies and Travellers in the UK, and they are invisible in national datasets. Gypsies and Travellers have never been included as a category in the national census, although the 2011 census will, for the first time, have a category of 'Gypsy and Irish Traveller'. What ethnic monitoring there has been

⁷ *Eric Pickles: time for a fair deal for the travelling and settled community*, press release, DCLG, 29 August 2010

⁸ *Progress report on Gypsy and Traveller policy*, Department for Communities and Local Government, July 2009

in the UK has been piecemeal, often on a service-by-service basis, and with variations in the terminology and categories used. Ethnic monitoring based on self-categorisation or self-disclosure may well result in under-reporting, with many Gypsies and Travellers reluctant to disclose their identity due to fears of prejudice, and a deeply engrained mistrust of authority. Until recently, informed estimates put the number of Gypsies and Travellers in the UK at between 120,000 and 300,000⁹. The Government now estimates that Gypsies and Travellers number around 368,000 in the UK, making up about 0.6% of the total population¹⁰. This compares with official estimates of around 360,000 Bangladeshi people and 409,000 Chinese people in England and Wales in 2007 (UK-wide figures not available)¹¹.

Cultural and ethnic composition of the Gypsy and Traveller population

There are a number of distinct ethnic groups and communities who make up the UK's Gypsies and Travellers population:

- English Gypsies (also known as Romany Gypsies)
- Scottish Gypsies or Scottish Travellers (also of Romany origin)
- Welsh Gypsies or Welsh Travellers (Kale) (also of Romany origin)
- Irish Travellers
- Roma people
- Bargees (boat dwellers)
- Show, fairground and circus people
- New Travellers

Romany Gypsies, Scottish Gypsies/Travellers, Welsh Gypsies/Travellers, and Irish Travellers are distinct groups, each with their own history, culture and traditions, but share many aspects of a common cultural identity and may have strong cultural ties. Membership of these groups is dictated by birth or marriage, and large extended families are common. English, Scottish and Welsh Gypsies are all of Romany origin; the origins of Irish Travellers are less well understood, and may be more mixed. English Gypsies or Romany Gypsies are the largest group in England, and have been estimated to make up perhaps half of all Gypsies and Travellers.

⁹ *NHS Primary Care Service Framework; Gypsies and Traveller Communities*, Primary Care Contracting, 2009

¹⁰ Figures from Cabinet Office 2010, cited in *Pacesetters Programme Gypsy, Roma and Traveller core strand, Evaluation Report for the Department of Health*, University of Sheffield, April 2010

¹¹ *Population estimates by ethnic group mid-2007 (experimental)*, Office for National Statistics, Feb 2010

Roma refers to Gypsy Travellers originating from Eastern and Middle European countries; many have arrived in recent decades in the UK.

Bargees are boat dwelling people who operate transport barges and vessels on inland waterways. They are considered occupational travellers.

Show People and **Circus People** are occupational travellers, and are not a distinct ethnic group.

New Travellers are a diverse group that reflect a lifestyle choice and are not a distinct ethnic group. Not all New Travellers have retained a mobile lifestyle, but in some families there are children who are third or fourth generation New Travellers.

New Travellers and Roma refugees from Europe are likely to experience different social and cultural influences on health, compared to English, Scottish and Welsh Romany Gypsies¹².

Under the Race Relations Act 1976, Romany Gypsies and Irish Travellers are recognised as minority ethnic groups, and afforded some protection in law against discrimination. As a result of this and subsequent race relations legislation, public bodies including the NHS and local authorities, are obliged to consider the needs of these groups. However, the official recognition of Romany Gypsies and Irish Travellers as minority ethnic groups has not resulted in their inclusion in ethnic monitoring conducted by many organisations, and therefore their invisibility has been perpetuated. Many local authorities, NHS services and other public bodies have been unable to meaningfully consider and respond to their needs because of a lack of data or knowledge. None of the other groups of Gypsies and Travellers cited above are recognised or protected by race relations legislation.

Age profile

The lack of systematic ethnic monitoring or census data means that it is not currently possible to provide an accurate age profile of the Gypsy and Traveller population. However, Gypsies and Travellers are known to have large families, with four or more children not considered unusual¹³. Parry cites a cultural desire for large families¹⁴. The largest and most in-depth research study to date on the health status of Gypsies and Travellers in England found that Gypsies and Travellers reported having significantly more children than those in an age-sex matched comparator group¹⁵. This coupled with the lower life expectancy of both men and women from Gypsy and Traveller communities (see section on Gypsies' and Travellers' Health and Health Needs, below), means that it is reasonable to assume that

¹² Research report: *Health status of Gypsies and Travellers in England*, Parry et al, JECH, 2007

¹³ Stakeholder interview

¹⁴ *The Health Status of Gypsies and Travellers in England*, report for Department of Health, Parry et al, University of Sheffield, October 2004

¹⁵ *The Health Status of Gypsies and Travellers in England*, report for Department of Health, Parry et al, University of Sheffield, October 2004

overall the Gypsy and Traveller population has a younger age profile than the general UK population.

The national schools census¹⁶ shows that in January 2010 there were just under 15,000 children classified as 'Traveller of Irish Heritage' or 'Gypsy/Roma' in state schools in England: around 10,000 in primary school, around 4,700 in secondary school, and 260 in special schools. These figures represent 0.23% of over 6.5 million children in state schools. However, the data are likely to under-represent the numbers of Gypsy and Traveller children in England because some families may not have disclosed to the authorities that they are Gypsies or Travellers, especially if they are currently living in settled accommodation. Some children of Irish Traveller origin may have been classified under the separate category of 'Irish'. Furthermore, it is known that school non-attendance rates amongst Gypsies and Travellers are higher than average, especially with children of secondary school age, and therefore some children may be 'lost' to the system and not recorded.

Where do Gypsies and Travellers in England live?

Gypsies and Travellers live in a number of different types of accommodation, and different locations. Although the homes of Gypsies and Travellers living on sites are officially referred to as 'caravans', these dwellings may in fact be touring or fixed-site caravans, mobile homes, trailers, and other living-vehicles, and on permanent sites they can also be small chalets. For the rest of this report, the term 'caravan' is assumed to cover all of these kinds of accommodation.

Roadside – Gypsies and Travellers refer to people currently living on unauthorised sites or encampments as "roadsiders". Roadsiders live in a nomadic way, in caravans that they frequently move, either by choice, or because of impending or actual enforcement proceedings requiring them to move on.

Unauthorised encampments often reflect the most transient members of the Gypsy and Traveller community, and are the hardest to quantify accurately. Some unauthorised encampments are never reported to the authorities and therefore go unrecorded. Unauthorised encampments can be for a single night or a few nights before people move on, or can last for many months. They may consist of a single touring caravan housing one family, or scores of vehicles such as touring caravans, trailers, mobile homes, cars, vans, lorries and horseboxes. Unauthorised encampments come to an end in a number of ways: Gypsies and Travellers moving of their own accord, either willingly or unwillingly; Gypsies and Travellers being evicted through civil procedures; or Gypsies and Travellers being evicted using Section 61 of the Criminal Justice and Public Order Act 1994 – a process Gypsies and Travellers refer to as "being sectioned".

Unauthorised developments are sites where Gypsies and Travellers are living without planning consent. Many unauthorised developments are on land that Gypsies and Travellers have bought and own legally. These sites may vary in size, and in the extent to which any development has taken place, for example tarmacked areas, roads, amenities, and demarcation of distinct plots.

¹⁶ *Schools, Pupils and their Characteristics: January 2010*, Department for Education, June 2010

Transit sites – some local authorities provide transit sites. These are authorised sites where Gypsies and Travellers may stay for a defined period of time, paying a daily charge, but must then move on. The maximum allowable stay varies from council to council, but usually ranges from 28 days to three months. Transit sites can also be privately owned and run. There are currently no transit sites in West Sussex.

Permanent authorised sites – these may be provided by a local authority, or people may live on private sites, often comprising just a few caravans on a small piece of land owned by one family. When the permanent site is run by a local authority, Gypsies and Travellers will typically pay a license fee for a plot on the site from the council and then separately rent or own their caravan. They also pay Council Tax and utility charges. The number, size and location of permanent sites in West Sussex is discussed in the section on Gypsies and Travellers in West Sussex, below.

Settled / bricks and mortar housing – this may be social housing provided by local authorities or housing associations, or some people may own their own homes. There are no official figures on the numbers of Gypsies and Travellers living in settled housing.

The Caravan Count, January 2010

One of the few sources of data about the Gypsy and Traveller population in England, and within each local authority area, is the 'Caravan Count': the government requires all local authorities to identify the number of Gypsy and Traveller caravans within their areas on 31 January and 31 July each year.

The Caravan Count has been conducted since 1979. However, the results must be treated with caution, as concerns have been repeatedly raised about the accuracy of the data. It is not unusual for Gypsies and Travellers to have more than one caravan or other kinds of living accommodation and/or vehicles on a given pitch. This applies both to people that are travelling and those currently staying on a permanent site. Someone living on a permanent site may have a fixed caravan or chalet, plus a touring caravan used when they travel, on the same pitch. It is not always obvious to those conducting the Caravan Count exactly how many of these are occupied at any one time, and therefore whether there may be more than one 'caravan' (as a unit of occupation and a proxy measure for households) on a given pitch. Different local authorities may have different ways of addressing these issues, or of recording the information, leading to inaccuracies and inconsistencies. In addition, in any given year a minority of local authorities do not provide Caravan Count figures to the DCLG, meaning that some under-reporting is likely, within the aggregate figures. Furthermore, the Caravan Count does not provide any information on Gypsy and Traveller households living in bricks and mortar housing.

Despite these qualifications, the Caravan Count does provide an important and useful overview of the size and location of the Gypsy and Traveller population who are not in settled housing.

Authorised local authority and RSL sites: the Caravan Count¹⁷ show that in England in January 2010 there were a total of 4,918 Gypsy and Traveller sites provided by local authorities and other registered social landlords (RSLs), with a combined caravan capacity of 8,172. Of these sites, 253 were transit sites, and the other 4,556 were classified as 'residential' (i.e. permanent sites). In the South East there were 1,034 sites, with a total caravan capacity of 1,419. Of sites in the South East, 40 were transit sites, and 994 were residential (permanent) sites.

Caravans: there were a total of 18,355 Gypsy and Traveller caravans on all types of site in England (local authority and private authorised sites plus unauthorised developments and encampments). Of these, the 2010 Caravan Count shows 3,753 were in the South East, including 339 in West Sussex¹⁸. There are no official figures for the number of people per caravan.

Caravans on private authorised sites: there were 7,866 caravans on private sites in England (43% of all caravans). In England as a whole, and in the South East, the number of caravans on private authorised sites has been consistently higher than the number of caravans on local authority sites, at successive Caravan Counts. However for West Sussex, caravans on local authority sites consistently outnumber those on private authorised sites.

Caravans on unauthorised sites: England had 2,395 caravans on unauthorised sites on land owned by Gypsies and Travellers (13% of all caravans), and 1,224 caravans on unauthorised sites on land not owned by Gypsies and Travellers (7% of all caravans).

In **West Sussex**, the figures were 82 caravans on authorised private sites (24% of all caravans), 59 caravans on unauthorised sites on land owned by Gypsies and Travellers (17% of all caravans), and 23 caravans on unauthorised sites on land not owned by Gypsies and Travellers (7% of all caravans).

Some Gypsies and Travellers travel throughout the year, others travel for only part of the year, and others do not travel and consider themselves settled, either on a permanent site, or in bricks and mortar accommodation. It is important to note that even people who have a plot on a permanent site, or who live in a house, may wish to travel for at least some of the time. For example, some families with children may stay in one place during the school term, but travel during the school holidays. Travelling is deeply embedded as a way of life and an emotional and cultural imperative for many Gypsies and Travellers. Gypsies and Travellers cannot be defined or identified solely by their current travelling status; rather, it must also be recognised that Gypsies and Travellers have strong and distinct cultural identities, practices and sets of beliefs. Gypsies and Travellers who are now living in settled housing do not

¹⁷ *Count of Gypsy and Traveller Caravans January 2010*, Department for Communities and Local Government, published May 2010

¹⁸ The 2010 Caravan Count shows an unusually high number of caravans, compared to previous years, at Horsham and Chichester local authority sites. Horsham, in particular, is listed as having 84 caravans, even though local authority site capacity is only 37. This may be an error, or reflect a short-term high occupation, inconsistent with usual occupation patterns. Our calculations on page 18 therefore use a more conservative estimate by assuming 124 caravans on local authority sites across West Sussex i.e. one caravan per pitch, and all pitches occupied. This is in line with what WSCC have told us is realistic pitch occupation.

cease to identify as Gypsies and Travellers, nor do they lose their beliefs and practices, simply because of their current accommodation situation.

Gypsies' and Travellers' distinctive culture

There are a number of distinctive features that characterise Gypsies' and Travellers' culture. Parry explains that cultural 'rules' exist, and that breaking these rules entails the risk of becoming 'outcast'¹⁹. Thus maintaining traditional modes of behaviour and adherence to cultural rules is a way of maintaining Gypsy and Traveller identity and passing this on to one's children, in a world perceived as both ignorant of this culture and hostile.

Families are organised according to strict hierarchies and gender roles; women are expected to look after the household, including being responsible for child-rearing, cooking and cleaning. Men are considered responsible for supporting the household financially. There is a strong emphasis throughout the culture, but especially for men, on self sufficiency, and against seeking help (financial, emotional, etc.) from outsiders. As 'head of household' men expect to be respected and deferred to by women and children. Men do not get involved in 'women's issues' and usually health matters are seen to fall within this realm. It is common for Gypsy and Traveller men to feel awkward and embarrassed talking about their own health problems, or those of their family members.

There are cultural expectations that people will marry, and having a large family is both an expectation and aspiration. The extended family is particularly important within Gypsy and Traveller culture. In many cases, members of the same extended family will expect to live close together, either on the same site, or nearby, and to travel together. Visiting or meeting up with family is a major reason for people to travel, both short and long distances. At times of illness or crisis, families will expect support from other family members, and long distances will be travelled in order to provide such support. It is common for groups of family members to attend hospital and sometimes medical appointments, and to expect to be involved in care, support, and sometimes decision-making about health issues.

There are also strong cultural beliefs and rules regarding cleanliness and pollution in Gypsy and Traveller culture. For example, separate bowls are required for washing food, plates, clothes, and the body; using the same bowl for these different functions is considered grossly unclean. Many Gypsies and Travellers feel very uncomfortable with the idea of anyone who is not a family member using their toilet. Wearing outdoor shoes inside the caravan or house may also be seen as unhygienic.

Having a clean home is considered an imperative, and for women, keeping the home clean is an important social role²⁰. Several of the stakeholders we spoke to commented on the fact that the Gypsy and Traveller homes they visited were 'always spotless', but also on the fact that women spent so much of their time cleaning. There are also strong beliefs regarding pollution, which can manifest in concerns about additives and unnatural foods, and also

¹⁹ *The Health Status of Gypsies and Travellers in England*, report for Department of Health, Parry et al, University of Sheffield, October 2004

²⁰ *The Health Status of Gypsies and Travellers in England*, report for Department of Health, Parry et al, University of Sheffield, October 2004

medications and possibly vaccinations and injections generally. Cleanliness, hygiene and keeping clean are strongly associated with good health. The EHRC report²¹ says that Gypsies and Travellers have a holistic concept of health that emphasises social and environmental factors as key determinants of health, rather than a medical model rooted in concepts of disease and medication.

Literacy and educational disadvantage

A notable feature of the Gypsy and Traveller population in England is that a high proportion have very poor levels of literacy. The University of Sheffield report found that "the educational disadvantage of the Travellers was extremely striking, and the single most marked difference between Gypsies and Travellers and other socially deprived and ethnic minority populations." An EHRC briefing paper²² says that "in 2003 less than a quarter of Gypsy and Traveller children obtained five GCSE and A* - C grades, compared to a national average of over half." Other reports show that Gypsy and Traveller children have the lowest educational attainment of any minority ethnic group²³ and the Department for Education says "Although numbers recorded in these ethnic categories are small, it is clear Gypsy/Roma pupils and Travellers of Irish Heritage pupils have very low attainment throughout Key Stage assessments. The evidence shows they are the lowest achieving group of pupils in our schools."²⁴

²¹ *Inequalities experienced by Gypsy and Traveller communities, a review*, Equalities and Human Rights Commission, 2009

²² *Gypsies and Travellers: simple solutions for living together*, EHRC, 2009

²³ see *Gypsies and Travellers strategy*, Brighton & Hove, 2007

²⁴ Department for Education website, July 2010

Gypsies and Travellers in West Sussex

The county of West Sussex is situated on England's south coast and borders the counties of Hampshire, Surrey and East Sussex. It is 769 miles² (1991 km²) in area. West Sussex has a population of some 792,900²⁵. It has a number of sizeable towns, with Worthing and Crawley both having populations slightly over 100,000. However, large parts of the county are rural, and much of the population lives in small towns, villages and hamlets.

Numbers of Gypsies and Travellers in West Sussex

As with the rest of the UK, the lack of systematic ethnic monitoring for Gypsies and Travellers means that it is impossible to accurately quantify the number of Gypsies and Travellers within West Sussex, at any given time. However, a number of data sources and pieces of research were considered, to try and provide a reasonable estimate.

The sources of data used were:

- Figures published by the Department for Communities and Local Government (DCLG) from the twice-yearly national 'Caravan Count' of Gypsy and Traveller sites
- The West Sussex Gypsy and Traveller Accommodation Needs Assessment (West Sussex GTAA) conducted in 2006 and published in 2007 (this excludes Chichester)
- The Chichester Gypsy and Traveller Accommodation Needs Assessment (Chichester GTAA) conducted in 2006 and published in 2007
- Ethnic monitoring data collected as part of the annual national schools census for state primary and secondary schools in England, and published by the Department for Education (formerly the Department for Children, Families and Schools). The most recent figures are for January 2010
- Information provided by the housing and planning departments of the districts and boroughs within West Sussex

Based on the information from these various data sources, we have calculated a *broad estimate* of the number of Gypsy and Traveller people living in West Sussex to be between 3,000 and 3,500. Our calculations are as follows:

- Assuming a total of 288 Gypsies' and Travellers' caravans in West Sussex, across all site types (124 on LA/RSL authorised + 82 on private authorised + 82 on unauthorised)
- Assuming one household per caravan, and 2.9 people per household living on a site²⁶, gives an estimated $288 \times 2.9 = 835$ Gypsies and Travellers living on all site types in West Sussex, January 2010

²⁵ *Population estimates for mid-2009*, Office for National Statistics, June 2010

²⁶ the West Sussex GTAA found an average of 2.9 people per household amongst respondents living on sites, *West Sussex Gypsy and Traveller Accommodation Needs Assessment*, published 2007, p.

- Assuming a ratio of 2:1 for Gypsies and Travellers living in bricks and mortar housing²⁷, to those living on sites, gives an estimated 576 Gypsies and Travellers households in bricks and mortar housing
- Assuming 4.2 people per household in bricks and mortar²⁸, gives an estimated 576 x 4.2 = 2,419 Gypsies and Travellers living in bricks and mortar in West Sussex, January 2010
- 835 + 2,419 = 3,254 people.
- This represents around 0.4% of the population of West Sussex.
- Based on this figure of 3,254 we estimate the number of Gypsies and Travellers in West Sussex to be between 3,000 and 3,500.

It should be noted that this is only a broad estimate, and one based on a number of untested assumptions, and it should not be taken as a definitive figure.

This compares with estimates of 2,300 people of Bangladeshi origin and 3,500 people of Chinese origin in West Sussex in 2007 (latest data available)²⁹.

More detailed information on the Gypsies and Travellers population of West Sussex, derived from these various data sources, is given below.

Schools data

The Government conducts an annual census for all state schools in England, and publishes breakdowns for the number of children by ethnic group. The schools census is one of the few sources of systematically collected national data about Gypsies and Travellers. The most recent figures for West Sussex, from the school census of January 2010, published in May 2010, are shown in the table below.

²⁷ Sussex Traveller Action Group (STAG) estimate that two-thirds of Gypsies and Travellers in West Sussex live in settled housing; this is based on national estimates.

²⁸ the West Sussex GTAA found an average of 4.2 people per household amongst respondents living in bricks and mortar accommodation, *West Sussex Gypsy and Traveller Accommodation Needs Assessment*, David Couttie Associates, published 2007, p. 41. However, the report points out that the sample size was small.

²⁹ *Population estimates by ethnic group mid-2007 (experimental)*, Office for National Statistics, Feb 2010

Table 1: ethnic breakdown of children in state schools in West Sussex, from annual schools census 2010, Department for Education

	Ethnic group (prim + sec)	Ethnic group (prim + sec)	Primary school	Primary school	Secondary School	Secondary School
	Number	Percentage	Number	Percentage	Number	Percentage
White British	80428	87.85%	41413	87.19%	39015	88.56%
Irish	254	0.28%	127	0.27%	127	0.29%
Traveller of Irish Heritage	29	0.03%	21	0.04%	8	0.02%
Gypsy Roma	228	0.25%	128	0.27%	100	0.23%
White other	2716	2.97%	1511	3.18%	1205	2.74%
Mixed	2720	2.97%	1560	3.28%	1160	2.63%
Asian	3490	3.81%	1910	4.02%	1580	3.59%
Black	1060	1.16%	520	1.09%	540	1.23%
Chinese	220	0.24%	100	0.21%	120	0.27%
Other	410	0.45%	210	0.44%	200	0.45%
Total (of ethnically classified)	91555	100.00%	47500	100.00%	44055	100.00%

This shows a total of 257 school children of Irish Traveller or Gypsy Roma origin, in state primary and secondary schools in West Sussex. Such children form 0.28% of the total of all ethnically classified children, and suggest comparable numbers in West Sussex with children of Chinese origin (220) and of Irish origin (254). However, it must be remembered that non-attendance rates at school - especially at secondary school - are high for Gypsies and Travellers children and therefore there is likely to be some under-reporting. The West Sussex GTAA found 16 households living on sites, who were identified as having school aged children not in school. Our interviews revealed that some Gypsy and Traveller families choose to have their children educated at home for reasons including concerns about bullying and cultural isolation, and unhappiness at children's exposure to sex education. Nevertheless, from these data we can infer that there were *at least* 257 school aged children from Gypsy and Irish Traveller families in West Sussex, in January 2010.

Where do Gypsies and Travellers live in West Sussex?

As in the rest of England, Gypsies and Travellers in West Sussex live on permanent authorised local authority sites, permanent authorised private sites, unauthorised developments and encampments, and in bricks and mortar housing.

'Snapshot' surveys like the Caravan Count are valuable, but nevertheless do not capture the complexity of a transient population. Many of the Gypsies and Travellers who live in West Sussex, and may use health and social care services, continue to travel for part or all of the

year, and therefore may also spend time in, and use services in, other parts of England, particularly the South East. Similarly, Gypsies and Travellers who consider themselves to live in other counties may still travel to West Sussex and require treatment, care and support from West Sussex services.

Most of the households identified in 2006 by the West Sussex GTAA³⁰ as having lived in their present accommodation for less than five years had come to West Sussex from East Sussex (nine implied households). One household had come from Surrey, and five had come from 'within the UK but outside the South East'. The West Sussex GTAA did not identify any households on either authorised or unauthorised sites who had come from Hampshire or Ireland. Although four years old, these are the most recent data available on Gypsy and Traveller migration patterns in West Sussex. The report says: "the data suggests that households moving into the study area will typically start by settling on an unauthorised site, those who remain for more than 12 months will typically find more settled, permanent site accommodation."

Local authority authorised sites

The table below shows the location of local authority authorised sites in West Sussex. All of these are well established, having opened between 1968 and 1976. They range in size from three to 23 pitches, providing a combined total of 124 pitches. The sites are managed by West Sussex County Council through a team of paid staff, including some resident site managers. The capacity of authorised local authority sites in West Sussex has been relatively stable in recent years, with all sites generally operating at full capacity. West Sussex County Council manages waiting lists for site places.

³⁰ *West Sussex Gypsy and Traveller Accommodation Needs Assessment*, David Couttie Associates, conducted 2006, published 2007

Table 2: Local authority authorised site provision in West Sussex, Caravan Count, Jan 2010

District/borough	Site name and location	No. pitches (of which transit)	Caravan capacity	Date opened	Date of last site changes
Adur	Withy Patch Lancing	12 (0)	12	1979	1997
Arun	Ryebank Yapton	12 (0)	12	1981	2003
Chichester	Easthampnett Marsh Lane	23 (0)	23	1978	1990
Chichester	Westbourne Cemetery Lane	14 (0)	14	1980	1993
Crawley	None	-	-	-	-
Horsham	Small Dole Henfield	12 (0)	12	1980	2006
Horsham	Adversane Billingshurst	13 (1)*	13	1979	Not known
Horsham	Cousins Copse Billingshurst	12 (0)	12	1979	Not known
Mid Sussex	Bedelands Burgess Hill	10 (0)	10	1968	Not known
Mid Sussex	Fairplace Hill Fairbridge Way Burgess Hill	8 (0)	8	1976	2005
Mid Sussex	Walstead Lindfield, Haywards Heath	5 (0)	5	1970	2004
Mid Sussex	Horsgate Cuckfield, Haywards Heath	3 (0)	3	1970	2006
Worthing	none	-	-	-	-
TOTAL		124 (1)*	124		

* Although the January 2010 Caravan Count shows one transit pitch at Adversane site, West Sussex County Council's Travellers and Enforcement Team Leader has confirmed to OPM that there are in fact no transit pitches at Adversane, or anywhere else in West Sussex.

Private authorised sites

The most recent figures show 82 private authorised Gypsy and Traveller sites across West Sussex, of which 71 have permanent planning permission. Caravans on authorised private sites have been concentrated in three districts: Chichester, Horsham and Mid Sussex, and increased in 2010, mainly due to increases in Chichester (Table 3 and 4).

Table 3: caravans on private authorised sites in West Sussex, Caravan Count, Jan 2010

District/borough	With temporary planning permission	With permanent planning permission	Total caravans on private authorised sites Jan 2010
Adur	0	0	0
Arun	0	0	0
Chichester	0	52	52
Crawley	0	0	0
Horsham	10	14	24
Mid Sussex	1	5	6
Worthing	0	0	0
TOTAL	11	71	82

Table 4: caravans on private authorised sites in W. Sussex, Caravan Counts Jul 07 to Jan 10

District/borough	Total caravans on private sites Jul 07	Total caravans on private sites Jan 08	Total caravans on private sites July 08	Total caravans on private sites Jan 09	Total caravans on private sites July 09	Total caravans on private sites Jan 10
Adur	0	0	0	0	0	0
Arun	0	0	0	0	0	0
Chichester	35	34	39	42	37	52
Crawley	0	0	0	0	0	0
Horsham	31	29	19	24	20	24
Mid Sussex	11	11	11	6	6	6
Worthing	0	0	0	0	0	0
TOTAL	77	74	69	72	63	82

Unauthorised sites

The figures for unauthorised sites include both unauthorised developments, and unauthorised encampments, recorded on the date of the Caravan Count. Those on sites owned by Gypsies and Travellers are more likely to be unauthorised developments (i.e. a development without planning permission), rather than unauthorised encampments.

In recent years, caravans on unauthorised sites in West Sussex have been concentrated in four areas: Horsham, Arun, Chichester and, to a lesser extent, Mid Sussex. In January 2010, there were 82 Gypsy and Traveller caravans recorded on unauthorised sites in West Sussex: 59 on land owned by Gypsies and Travellers, and 23 on land not owned by Gypsies and Travellers. The number of caravans recorded on unauthorised developments and encampments increased in 2010.

It should be noted that Crawley Borough Council did not provide figures for the January 2010 Caravan Count, therefore the data exclude Crawley.

Table 5: caravans on unauthorised sites in West Sussex, Caravan Count, Jan 2010

District/borough	Caravans on land owned by Gypsies and Travellers	Caravans on land not owned by Gypsies and Travellers	Total caravans on unauthorised sites Jan 2010
Adur	0	0	0
Arun	16	0	16
Chichester	13	0	13
Crawley	-	-	-
Horsham	27	23	50
Mid Sussex	3	0	3
Worthing	0	0	0
TOTAL	59	23	82

Table 6: caravans on unauthorised sites (without planning permission) in West Sussex, Caravan Counts Jul 07 - Jan 10

District/borough	Total caravans on unauthorised sites Jul 07	Total caravans on unauthorised sites Jan 08	Total caravans on unauthorised sites Jul 08	Total caravans on unauthorised sites Jan 09	Total caravans on unauthorised sites Jul 09	Total caravans on unauthorised sites Jan 10
Adur	0	0	0	0	0	0
Arun	28	6	7	16	9	16
Chichester	15	14	13	12	9	13
Crawley	0	0	0	0	0	0
Horsham	21	14	27	19	21	50
Mid Sussex	2	11	3	4	10	3
Worthing	0	0	0	0	0	0
TOTAL	66	45	50	51	49	82

Comparison with West Sussex GTAA and Chichester GTAA

The West Sussex GTAA was conducted in 2006, and published in 2007. It was commissioned by WSCC, in conjunction with six of the seven borough and district councils in West Sussex (excluding Chichester), and carried out by David Coultie Associates (DCA). Although older than the data from the January 2010 Caravan Count, the West Sussex GTAA provides a more detailed breakdown of the location of Gypsies and Travellers in West Sussex, and estimates of the number of households, in addition to information about the number of sites, pitches and caravans.

Chichester District Council commissioned its own Gypsy and Traveller Accommodation Needs Assessment. The research was conducted from January to November 2006, and the report published in June 2007. The findings can therefore be read in conjunction with the West Sussex GTAA of 2006.

Numbers living on authorised sites: 2006 and 2010

The West Sussex GTAA estimated there were 115 Gypsy and Traveller households living in authorised sites (local authority and private) in West Sussex, in July 2006. OPM has combined the data from the West Sussex GTAA and Chichester GTAA, and assumed one household per pitch, and 100% occupancy of all Chichester pitches, to produce an overall estimate of 178 Gypsy and Traveller households on pitches on authorised sites (local authority and private) across West Sussex in 2006.

The estimate of 178 Gypsy and Traveller households on authorised sites in West Sussex in 2006, compares with the January 2010 Caravan Count figure of 206 (124 + 82; assuming one household per pitch).

Numbers living on unauthorised sites: 2006 and 2010

The West Sussex GTAA estimated there were 30 households living on unauthorised sites in West Sussex excluding Chichester in July 2006. The Chichester GTAA estimated 13 households on unauthorised sites. OPM has combined the data from both GTAAs, to give an overall estimate of 43 households on unauthorised sites in West Sussex, in July 2006. This compares with the January 2010 Caravan Count figure of 82 caravans on unauthorised sites in West Sussex.

Thus, the figures appear to indicate that the numbers of Gypsies and Travellers living on both authorised and unauthorised sites in West Sussex have increased between 2006 and 2010. Reasons for this increase may include family growth and increased migration into West Sussex.

Bricks and mortar accommodation

There are no official figures for the numbers of Gypsies and Travellers living in settled housing / bricks and mortar accommodation in West Sussex. The West Sussex GTAA states that the number of Gypsies and Travellers households living in bricks and mortar accommodation is not known. The Chichester GTAA reports that, following requests to the council's registered social landlords (RSLs) for information regarding numbers of Gypsies and Travellers in social housing "it became apparent ...that such records are not maintained." However, groups working closely with Gypsies and Travellers in West Sussex estimate that around two-thirds of Gypsies and Travellers live in housing, based on national estimates³¹.

Information provided by local authorities to OPM

In order to bring up-to-date the information from the West Sussex GTAA and Chichester GTAA, OPM contacted all seven of the districts and boroughs within West Sussex, and asked them to provide updated information on Gypsies' and Travellers' authorised and unauthorised sites, and any other relevant developments that were known about or anticipated. The information that we received was mixed; some provided detailed information about existing sites and planning applications and enforcement notices, whilst others provided minimal information, although sometimes this was because there were no sites in their areas. One local authority told us they were uncertain whether the figures they had were from before or after the 2006 West Sussex GTAA.

The information provided by local councils show that most private sites in West Sussex are small scale, comprising between one and five pitches, in rural locations. Most private sites appear to run at full occupancy. They have often been occupied by the same families for many years or decades. Even for well established sites, it can be difficult for local authorities to maintain up-to-date accurate information about the number of pitches or units on the site, and about actual occupancy.

³¹ Sussex Travellers Action Group powerpoint presentation, 11 March 2009

The information received from local councils can be summarised as:

Table 7: summary of information from W. Sussex district & borough councils, June-July 2010

District/borough	Information provided
Adur	Confirmed 2010 Caravan Count information about local authority site No further information about private sites No further information about unauthorised sites
Arun	Information about private sites and planning applications
Chichester	Information about planning applications
Crawley	Responded that there are no sites in the area
Horsham	Information about existing local authority and private authorised sites, and about planning applications
Mid Sussex	Information about authorised local authority and private sites
Worthing	Responded that there are no sites in the area

Arun

- 1 local authority site run by WSCC at Ryebank, Yapton, pitch capacity of 11, occupancy of 11
- 4 private authorised permanent sites, combined pitch capacity of 6, occupancy of 6
- 2 private sites with temporary planning permission, combined pitch capacity of 12, occupancy of 12
- 1 private unauthorised site, enforcement action ongoing, 1 caravan
- 2 authorised sites for Travelling Showpeople (required to be members of Showman's Guild of Great Britain), maximum combined capacity of 40 caravans, current occupancy unknown
- 2 further private temporary sites, each with 1 caravan, unclear current planning status

Chichester

Chichester provided more detailed information about pitch capacity, giving details of the number of mobile homes, touring caravans, etc. on each site. These have been described here as 'units' but it is not possible to tell whether a 'unit' here equates to a pitch in another local authority.

- 1 local authority site run by WSCC at Westbourne, pitch capacity of 14, occupancy of 14
- 1 local authority site run by WSCC at Easthampnett, Tangmere, pitch capacity of 22, occupancy of 22
- 9 private authorised permanent sites
- 1 private mixed site, capacity of 5 units, occupancy 5 units

Horsham

- 1 privately owned but local authority run site, run by WSCC, at Small Dole, pitch capacity 17, occupancy of 12 (plus additional unauthorised, tolerated)
- 1 local authority site run by WSCC at Adversane, pitch capacity 12, occupancy 12
- 1 local authority site run by WSCC at Cousins Copse, pitch capacity 12, occupancy 12
- 12 private authorised permanent sites, with combined pitch capacity of 25, occupancy of 24
- 2 private sites with temporary planning permission, combined pitch capacity of 5, occupancy of 4
- 1 private permanent site for circus and travelling showpeople, capacity and occupancy unknown, subject to needs assessment

Mid Sussex

- 1 local authority site run by WSCC at Bedlands Farm, Burgess Hill, pitch capacity 10, occupancy 10
- 1 local authority site run by WSCC at Fairplace Hill, Fairbridge Way, Burgess Hill, pitch capacity 8, occupancy 8
- 1 local authority site run by WSCC at Walstead, Haywards Heath, pitch capacity 5, occupancy 5
- 1 local authority site run by WSCC at Horsgate, Cuckfield, Haywards Heath, pitch capacity 3, occupancy 3
- 3 private authorised permanent sites, combined pitch capacity 12, occupancy 12
- 1 private site, temporary permission, pitch capacity 1, occupancy 1
- 1 private site, status unknown, pitch capacity 1, occupancy 1

Crawley

Crawley did not submit information to the DCLG for the January 2010 Caravan Count, and its official figures therefore show nil sites. The borough council also told us there were no sites in the area. However, the West Sussex GTAA contains information on the number of caravans on illegal encampments on WSCC land between 2000 and 2006. This showed a total of 660 illegal encampments in Crawley for this 6.5 year period, by far the highest number in any of the district or borough council areas. Furthermore, the West Sussex GTAA says that based on local knowledge, Crawley also had the highest number of encampments on private land, in 2006.

Worthing

The most recent official figures for Worthing show nil authorised or unauthorised sites and the borough council told us there were no sites in the area. However, the West Sussex GTAA contains information on the number of caravans on illegal encampments on WSCC land between 2000 and 2006, showing a total of 108 illegal encampments in Worthing during that 6.5 year period, with two years for which the figures were not known.

OPM asked Sussex Police whether they had any insight into why illegal encampments in Crawley and Worthing had declined so dramatically. They told us that their records show very few unauthorised encampments in Crawley in 2010 (two encampments, involving total of five caravans), and that such encampments in Crawley now seem to be small-scale and short-term in nature. Their records did not show any unauthorised encampments in Worthing this year. This appears to confirm that the information from Crawley and Worthing borough councils is accurate. Sussex Police did not have any explanation for the change. However, they said that they were aware of higher numbers of unauthorised encampments in Brighton and Hove in recent times, so it is possible that Gypsies and Travellers are simply choosing to travel to Brighton and Hove rather than Crawley and Worthing.

Geographic spread of Gypsies and Travellers within West Sussex

The Chichester GTAA³² says: "mapping evidence clearly shows that a high proportion of the district's Gypsy and Traveller settled community resides in the south of the district, within reach of the A27 corridor. Unauthorised encampments and developments are also prominent in this location as shown by the record of unauthorised encampments contained within this report."

The West Sussex GTAA says there were particular concentrations of unauthorised encampments in the east of the county: Crawley, Horsham and Mid Sussex, along the London – Brighton route, and that local information also suggested a typical East-West movement along the A27.

Many Gypsies and Travellers in West Sussex follow seasonal patterns of travelling. Both the West Sussex GTAA and the Chichester GTAA reported that movement was predominantly in the summer, with May, June, July and August being the peak months for people to travel.

Community relations and accommodation issues

As in other parts of the UK, in West Sussex tensions between the settled population and Gypsies and Travellers have tended to arise over issues relating to unauthorised sites, encampments and developments. Historically, most tensions arose when Gypsies and Travellers moved onto land owned by other people, and attempted to stay there. In more recent years, tensions have also arisen in some cases when Gypsies and Travellers have bought land, and started development without planning permission. Typically this may involve laying down tarmac or concrete, creating or moving mounds of earth, and using heavy machinery. Sometimes the land is in green belt areas or places considered unsuitable for residential development.

³² *An Assessment of the Accommodation Needs of Gypsies and Travellers in the District of Chichester*, Chichester District Council, June 2007

Stakeholders and Gypsies and Travellers we spoke to confirmed that in their experience, most Gypsies and Travellers on unauthorised encampments want to move onto permanent sites, but are unable to do so because there are simply not enough authorised sites available, and those that exist have long waiting lists. Most of the people we spoke to said they would prefer to live on a safe, high quality site with good facilities, rather than in bricks and mortar housing. In some parts of the country, local authorities have made the case for investing in development of authorised Gypsy and Traveller sites, arguing that the costs are more than offset by the reduced costs of enforcement against unauthorised encampments and developments. Bristol City Council, for example, saw enforcement costs drop from £200,000 to £350,000 per year in the mid-1990s to £5,000 per year, after creating two authorised sites, one transit and one permanent.³³

In recent years, Sussex Police have worked with the Sussex Traveller Action Group and Gypsy and Traveller community to set up a Gypsy and Traveller advisory group, chaired by a member of the Gypsy community, and meeting quarterly. The group scrutinises use of Section 61 (of the Criminal Justice and Public Order Act 1994) by the police to move on Gypsies and Travellers who are camping illegally. The group provides a forum for Gypsies and Travellers, the police and others to discuss how and why Section 61 orders are being used, and look at alternative approaches. Stakeholders told us that since the group was created, there has been a fall in the use of Section 61 orders, with more mediation and public education leading to more cases of unauthorised encampment being resolved without resorting to criminal law.

When Gypsies and Travellers own land but start development without planning permission, local authorities may issue enforcement notices requiring compliance with planning consent. There is a right of appeal against an enforcement notice. Councils can also issue stop notices, requiring development to cease; these have no right of appeal. Undertaking development without planning permission is not a criminal offence, but failure to comply with an enforcement notice is. These cases can take months, or longer, to resolve through the appeals process, during which time the Gypsies and Travellers, as legal owners of the land, can continue to occupy it.

In some parts of the country, people in settled communities have voiced resentment that they believe that there is 'one law for Gypsies and Travellers, and one for everyone else'. In other words, they perceive that Gypsies and Travellers are not being made to comply with planning legislation in the same way as other people. Gypsies and Travellers, conversely, perceive that they are less likely to be granted planning permission than settled people, and that the bias in the system is against them, rather than in their favour.

In response to this issue, the coalition government has said it intends to curb the ability to apply for retrospective planning permission³⁴. The current planning guidance approach is that a council should not take enforcement action in cases where it would have granted planning permission, if an application had been made. The government will need to ensure that its new measures do not single out and discriminate against Gypsies and Travellers as a

³³ Example cited in *Gypsies and Travellers: simple solutions for living together*, EHRC, 2009

³⁴ See *Gypsies and Travellers: unauthorised developments*, House of Commons Library briefing note SN/SC/3248, July 2010

distinct ethnic group, whilst at the same time ensuring they are not so draconian that they rule out anybody's ability to apply for retrospective planning permission, in any situation.

The government has also announced a Community Right to Build policy, under which people in rural areas will be able to build local housing projects on green belt land without planning permission as long as 75 per cent of the local community agree in a referendum. The measures will be contained in the forthcoming Localism Bill³⁵. It remains to be seen whether this legislation will make it easier or harder for Gypsies and Travellers to buy land and develop accommodation on it legally. However, it is likely that strong local opinion-leadership and improved public education will be important factors in whether housing projects for Gypsies and Travellers receive referendum approval.

A further change that will impact on Gypsies' and Travellers' ability to obtain planning permission for development of housing on their own land is the creation of the South Downs National Park Authority. This was established in shadow form in April 2010, and becomes fully operational in April 2011. It will become the planning authority for the whole national park area – stretching from Eastbourne to Winchester, and covering a substantial part of West Sussex. Once again, the implications for Gypsies and Travellers seeking planning permission within the South Downs National Park area are currently unclear, but it may become harder for them, and others, to achieve permission for development in a protected area.

³⁵ *Grant Shapps calls on communities to prepare for their Right to Build*, DCLG press release, 22 September 2010

The health and health needs of Gypsies and Travellers

Life expectancy and mortality

A 1987 study of Travellers' health in Ireland found a higher mortality rate for all causes in the Gypsy and Traveller population. For Gypsy and Traveller women, life expectancy was almost 12 years less, and for Gypsies and Travellers men almost 10 years less, than for the non-Traveller population.³⁶

In the UK, it is now officially recognised that Gypsies and Travellers have a significantly lower life expectancy than the general population³⁷. However, a lack of comparable data means that it is not possible to accurately quantify how much shorter the life expectancy of UK Gypsies and Travellers is, compared to the general population³⁸. One study in 2005³⁹ found that only 3% of Gypsies and Travellers in Leeds were aged over 60, although the life expectancy of the general population in Leeds was 78 years.

The EHRC report⁴⁰ says the evidence suggests that among Gypsies and Travellers with access to secure council sites or private sites, and who have access to adequate medical care, life expectancy may be closer to that of the general population. Within the UK, there is some evidence that Irish Travellers may have a lower life expectancy than English Gypsies, and the EHRC says "the lower life expectancy in Irish Traveller populations may result from poorer health status and an increased tendency to reside on unauthorised sites or in housing."

Gypsies and Travellers have infant mortality rates three times higher than the general population⁴¹. Rates of miscarriage and stillbirth are also higher.⁴²

The EHRC report says "premature deaths among young Gypsies and Travellers as a result of road traffic accidents are reported anecdotally, often associated with alcohol use and high-speed driving."⁴³

³⁶ Cited in *The Health Status of Gypsies and Travellers in England*, report for Department of Health, Parry et al, University of Sheffield, October 2004

³⁷ For example, CRE, 2004

³⁸ *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

³⁹ Baker cited in *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

⁴⁰ *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

⁴¹ Baker cited in *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

⁴² *The Health Status of Gypsies and Travellers in England*, report for Department of Health, Parry et al, University of Sheffield, October 2004

Poorer health than general UK population and other deprived groups

Gypsies and Travellers have significantly poorer health outcomes, compared with the general population of England, and with other English-speaking ethnic minorities. In 2004, a team from the University of Sheffield, commissioned by the Department of Health, conducted the first large-scale epidemiological study of Gypsies and Travellers health in England⁴⁴. The report concluded "it is clear that the scale of health inequality between the study population and the UK general population is large, with reported health problems between twice and five times more prevalent." It also said that "overall, Gypsies and Travellers are significantly more likely to have a long-term illness, health problem or disability which limits their daily activities or work." The research found that "Gypsies and Travellers had more problems with mobility, self-care, usual activities, pain or discomfort, and anxiety or depression... [and] reported statistically significant worse health status than their age-sexed matched comparators."

The most marked inequalities in Gypsies' and Travellers' health, compared to the general population and other ethnic minorities, were for respiratory problems including asthma and bronchitis, chest pain, and self-reported anxiety. Self-reported arthritis was also more prevalent in Gypsies and Travellers. "Nearly five times as many Gypsies and Travellers reported symptoms of chronic bronchitis than a general population in Sheffield and over twice as many reported asthma-like symptoms or symptoms of angina."⁴⁵

The Sheffield University team did not find inequality in relation to diabetes, stroke and cancer. Their analysis states that there may be a genuine lack of health inequality for these illnesses, or "alternatively, as cancer and type II diabetes tend to be 'silent' diseases until their later stages, they may have been under-reported in the Gypsies and Travellers group through ignorance of the diagnosis."

Chronic health problems and multiple health needs

Parry's report found that many Gypsies and Travellers have chronic and multiple health problems. The study found that 42% of Gypsies and Travellers participating in the research reported limiting long-term illness, compared with 18% of the general population in the 2001 census.

Quality Adjusted Life Years

Quality Adjusted Life Years, or QALYs, are a way of taking into account both the quantity (i.e. length) of life, but also the quality of life, when looking at the burden and impact of disease and ill-health. They are calculated by assigning each year of perfect health a value of 1.0,

⁴³ *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

⁴⁴ *The Health Status of Gypsies and Travellers*, report to Department of Health, Parry et al, University of Sheffield, 2004

⁴⁵ Research report: *Health status of Gypsies and Travellers in England*, Parry et al, JECH, 2007

death is given a value of 0, and each year of life with less-than-perfect-health, for example due to the effects of living with a particular disease or condition, is given a score somewhere between 0 and 1, according to the impact of that condition on quality of life.

The Sheffield University research found that assuming an average life expectancy of 75 years, Gypsies and Travellers would expect 56.25 QALYs, compared with 62.25 for an age-sexed match comparator group, and that "furthermore, the magnitude of the difference would be even larger if account is taken of the lower life expectancy of Gypsies and Travellers."⁴⁶

Health problems reported by interviewees

Our interviews with Gypsies and Travellers confirmed a picture of chronic and multiple health problems as common within the community. Amongst the people we interviewed, the following health problems were cited:

Table 8: health problems experienced by Gypsies and Travellers interviewed

Mental health	<ul style="list-style-type: none"> • Anxiety, panic attacks, depression, possible bipolar disorder • Depression, anxiety, paranoia • Getting "nervous" and having "a nerve disorder" [anxiety] • Taking anti-depressants and sleeping pills, previously sectioned several years ago (following death of own child) • Taking anti-depressants
Diabetes	<ul style="list-style-type: none"> • Type II diabetes (cited by two people)
Mobility	<ul style="list-style-type: none"> • Difficulty walking; mobility problems • Mobility problems; suspected arthritis • Mobility problems • Arthritis (cited by two people) • Osteo-arthritis, joint and back pain
Respiratory	<ul style="list-style-type: none"> • Asthma
Heart	<ul style="list-style-type: none"> • Have had three heart attacks • Heart aneurism • Angina and heart problems
Kidney	<ul style="list-style-type: none"> • Kidney trouble • Kidney problems
Brain	<ul style="list-style-type: none"> • Brain tumours, dizziness and blackouts

⁴⁶ Research report: *Health status of Gypsies and Travellers in England*, Parry et al, JECH, 2007

Migraine / headache	<ul style="list-style-type: none"> • Migraines (cited by two people) • Headaches
Other pain	<ul style="list-style-type: none"> • Pain • Back pains • Earaches
Eyes / vision	<ul style="list-style-type: none"> • Severely limited vision • Cataracts • Poor eyesight
Dental / oral	<ul style="list-style-type: none"> • Missing teeth
Other	<ul style="list-style-type: none"> • Possible Long QT syndrome – genetic condition; tests underway • Stomach problems • Trouble with ‘my water’ going to toilet • Black-outs • Being overweight • Feeling run down • Repeated miscarriages • Intermittent claudication: problem with joints in legs

In addition to these chronic problems, some of the younger people responded to being asked about their health by telling us that they had experienced measles, chickenpox, and recurring tonsillitis.

Health problems amongst family members cited by interviewees

We also asked people to tell us about ill-health amongst their family members, leaving it to each interviewee to define ‘family’. The responses are summarised in the table below.

Table 9: ill-health amongst family members cited by Gypsies and Travellers interviewed

Wife	<ul style="list-style-type: none"> • anxiety, depression, has had a breakdown, suicidal thoughts, losing hearing
Mothers	<ul style="list-style-type: none"> • rheumatoid arthritis, diabetes, thyroid problems • asthma, claustrophobia, nervousness, joint problems • ‘nerves’ [anxiety]
Fathers	<ul style="list-style-type: none"> • open heart surgery, high blood pressure, high cholesterol • high cholesterol
Sisters	<ul style="list-style-type: none"> • diabetes • fits • cysts • hysterectomy and early menopause
Brothers	<ul style="list-style-type: none"> • autism (adult) • possible eating disorder (young person)
Grandfathers	<ul style="list-style-type: none"> • paranoid schizophrenic* • Three strokes, now in wheelchair
Grandmothers	<ul style="list-style-type: none"> • heart attack • Depression*
Uncles / aunts	<ul style="list-style-type: none"> • Several aunts and uncles* – depression, including one aunt who was ‘put away for depression’
Children	<ul style="list-style-type: none"> • Asthma (several children in same family) • Cystic Fibrosis (several children in same family) • One child with CF has arthritis in legs • ADHD • possible autism, development and speech and language problems
Other	<ul style="list-style-type: none"> • Brother-in-law - Parkinson’s disease • Nephew – speech and language problems

*reported by same interviewee, who cited a family history of serious mental health problems

Interestingly, none of the women mentioned the health of their partners or spouses in response to this question. This may be because the cultural taboo around discussion of

men's health is so strong that they themselves were unaware of health problems experienced by their partners, or that they were aware of them but not comfortable disclosing or discussing them with strangers. However, interviewees appeared comfortable discussing the health of other men in their families such as fathers, brothers, and grandfathers.

It is also notable that nobody mentioned cancer, even though statistically it is highly likely that some of the interviewees would have relatives who have experienced cancer; around one in three of the UK population develops some form of cancer during their lifetime⁴⁷. Again, this may be because of cultural fears and taboos, making people unwilling to talk about cancer either within their own families, or to us. Alternatively, it could be that delayed presentation and low take up of screening services may result in a higher than average proportion of cancers going undiagnosed within the Gypsy and Traveller population. One woman disclosed much later in the interview, when talking about men's health and men's reluctance to see doctors, that her father was dying from cancer "*perhaps if it had been sooner, they might have been able to have helped him.*"

Discussing findings on attitudes to screening and diagnosis amongst Gypsies and Travellers, Parry reports that "death is seen as inevitable following a diagnosis of cancer and some view the diagnosis itself as being implicated in the prognosis. Many avoid the opportunity of diagnosis because of this fear. A fatalistic attitude of many Travellers is associated with a lack of conviction in the purpose of screening and other preventative health measures. This belief is compounded by fears of a potentially fatal diagnosis." During the qualitative part of the research, Parry's report says, "we noted at one venue there was clear distraction when cancer was mentioned – at that point in the presentation people started moving around and changing the subject."⁴⁸

Beliefs and attitudes to health

The research evidence shows that Gypsies and Travellers have a culturally distinct and identifiable set of beliefs and attitudes to health. One feature is a strong belief in self-reliance⁴⁹ which is likely to result in an aversion to seeking help or support from statutory services or others. There is also stoicism about poor health and pain, and a belief that these things must simply be tolerated. Another feature is a fatalistic and nihilistic attitude to health ('what will be, will be'), resulting in a view that illness is inevitable, and therefore seeking treatment is pointless. Fear of certain illnesses, including cancer and other terminal illnesses, combined with this fatalism, mean that many Gypsies and Travellers may avoid health screening. All of these beliefs, taken together, are likely to result in very late presentation of Gypsies and Travellers to GPs and other health services, when they do experience health problems or symptoms.

⁴⁷ Cancer Research UK website, September 2010

⁴⁸ *The Health Status of Gypsies and Travellers*, report to Department of Health, Parry et al, University of Sheffield, 2004

⁴⁹ *The Health Status of Gypsies and Travellers*, report to Department of Health, Parry et al, University of Sheffield, 2004

Parry⁵⁰ says "strong ethnic identity, and coherent cultural beliefs and attitudes, underpin health-related behaviour in this group, and health experiences need to be understood in this context, alongside the specific effect of the social and economic hardship, and social exclusion."

Sources of health knowledge

We asked Gypsies and Travellers where they obtained their knowledge of what constitutes good health, and how to keep healthy. The most cited source of information was from family members, specifically mothers.

- Mum (cited several times)
- Mum and Nan
- Parents teach you
- Family
- Newspapers
- Letters the kids bring home from school, e.g. about healthy eating
- Telly
- Television: *"if we have electricity to watch the television. Half the time there's no petrol for the generator."*
- *"Someone from FFT comes and tells you"*
- *"You just know"*
- Teacher giving talks at school
- Library, for books on food, dieting and healthy eating

Several people responded to this question by telling us that they had learnt from their mothers about cooking and eating, and cleanliness and hygiene. The responses illustrated the very close link between that these concepts and health in people's minds.

It is notable that none of the people we interviewed mentioned health professionals, in response to this question.

Source of information about health and care services

We asked where people got their information specifically about health and care services. Once again, family, friends and word-of-mouth were frequently cited: *"Someone always knows. If I don't know, she knows or her aunty or uncle or grandmother knows. Someone always knows, you just ask."* A young woman told us: *"Mum. She's been round here all her life, so she knows everything around here."*

⁵⁰ Research report: *Health status of Gypsies and Travellers in England*, Parry et al, JECH, 2007

Another key way in which people found out about other services was through being referred by their GP. People gave us examples of finding out about clinics, chiropody services and mental health services in this way.

Organisations with a specific remit to provide information and advice to Gypsies and Travellers were cited; Friends, Families and Travellers (FFT), and the Community House at Denham Road in Burgess Hill, were mentioned. However, Gypsies and Travellers told us that since the post of the Project Manager at the Denham Road Community House was made redundant in 2010, they no longer viewed this as a supportive and trustworthy source of support.

Site managers at council run sites were another source of such information. Dealing with external agencies and services, assisting residents, and helping them to complete forms, are parts of the WSCC site manager job description. It was clear from the interviews that there was considerable variation in the degree of trust held by different interviewees in the site managers. Some participants spoke very positively about their site managers, and told us they got on very well with them, even though the site managers were non-Travellers. At one site we were told the site manager was very good at helping out and providing people with support and information, above and beyond the requirements of their role. However, it was apparent from other interviews that not all site managers are seen in this way, and some interviewees conveyed a much greater sense of mistrust and suspicion of their site managers.

Some people told us that they use the internet to find such information, and again, the former Project Manager of the Community House at Denham Road had played a role by teaching people how to use the internet.

Interviewees told us that when they are travelling and need Accident and Emergency services, they "*just look for A&E signs*" in the town they are in.

These findings re-enforce the central importance of word-of-mouth and the reliance on trusted, established relationships in transmitting knowledge and information about both good health (health education and promotion) and about health and social care services, for members of the Gypsies and Travellers community.

Women's health and maternal health

The biggest gender difference found by the Sheffield University team was in relation to anxiety: "women were twice as likely as men to be anxious, even when education, smoking and career status was taken into account."⁵¹

The Sheffield University report noted the excess prevalence of miscarriages, stillbirths, neonatal deaths and premature deaths of older offspring. The EHRC says that Gypsy and Traveller mothers are twenty times more likely than the rest of the population to have experienced the death of a child⁵². The report of the Confidential Enquiries into Maternal Deaths in the UK 1997 – 1999 found that Travellers "have possibly the highest maternal

⁵¹ *The Health Status of Gypsies and Travellers*, report to Department of Health, Parry et al, University of Sheffield, 2004

⁵² *Gypsies and Travellers: simple solutions for living together*, EHRC, 2009

death rate amongst all ethnic groups." Substandard care was implicated in 5 out of 6 maternal deaths examined in the Confidential Enquiry.

A report on *Maternity Services and Travellers*⁵³ said that Gypsy and Traveller women may not gain full access to maternity services for a variety of reasons, and this can lead to a lack of continuity of care, especially for those who are highly mobile⁵⁴. The EHRC report⁵⁵ cites limited information on the importance of ante-natal monitoring, enforced movement, or being unsure how to access services as some of the reasons why Gypsy and Traveller women have poor access and uptake of maternity services. The report says "being forced to move on results in a lack of continuity of care, the treatment of symptoms rather than causes, the late detection of abnormalities, and sometimes the misdiagnosis of maternal and child health complications."

Most of our interviewees did not articulate any particular concerns or issues relating to maternity services and maternal health, and indeed many spoke positively about the care they had received from midwives and whilst having their children. However, one interviewee told us she had experienced repeated miscarriages, and was unhappy with the quality of support – emotional and medical – that she had been offered. At least one other interviewee had experienced the death of a child, for which she had received counselling, and continued to take anti-depressants and sleeping pills.

Several of the women we interviewed spoke to us about their mental health problems, and our findings appear to confirm that poor mental health is a widespread and chronic problem for many women in the Gypsy and Traveller community. Although several interviewees told us of male relatives who had experienced poor mental health, none of the men we spoke to disclosed any information about their own mental health, and we did not gain any qualitative data about men's experience of mental health from the interviews.

Children's health

Parry⁵⁶ reports that previous, small scale and descriptive studies indicate high infant mortality and perinatal death rates, low birth weight, low immunisation uptake, and high child accident rates, within the Gypsy and Traveller community. Poor quality sites and difficulty for parents in accessing appropriate information about accident prevention are both thought to be factors contributing to high child accident rates. The EHRC report says that "low levels of immunisation for children can be a particular problem where families are highly mobile, continuity of care is lacking, and specialist health visitors for the Gypsy and Traveller community are not available" and "concerns over the possible ill-effects of inoculations can also be an issue."

The Gypsies and Travellers we interviewed were mainly positive about their experiences of midwifery, maternity, health visiting and other children's health services. Interviewees talked

⁵³ *Maternity Services and Travellers*, Maternity Alliance, 2006

⁵⁴ *The Health of Gypsies and Travellers in the UK*, Matthews, Race Equality Foundation, Better Health Briefing Paper, 2008

⁵⁵ *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

⁵⁶ *Research report: Health status of Gypsies and Travellers in England*, Parry et al, JECH, 2007

much more about the wider factors affecting the health of their children – such as the quality and safety of sites, impact of noise, and lack of safe play areas - than about quality of children's health services. These issues are discussed in the sections on accommodation and impact on health, below.

Immunisations

Several people we spoke to told us they had a fear or dislike of "needles". This may be culturally embedded, perhaps linked with a fear of contamination. Some people told us that their children had received all their immunisations. However, given the low levels of literacy and health knowledge amongst many Gypsies and Travellers, it is not clear whether people are always fully aware of all the immunisations contained in the standard childhood programme. Thus some Gypsies and Travellers may believe that their children have had all the immunisations in the programme, but be unaware of immunisations that have been missed.

Other interviewees were more wary about immunisations: *"I take care of all that. There's certain vaccinations I won't let the kids have. They have had vaccinations but only the ones I want them to have."* This interviewee told us that MMR was one of the vaccinations that she would not let her children have, and that her son had been hospitalised with measles. She did not appear to have any regrets over her decision, which had been a seriously considered one, and influenced by her GP, with whom she'd been registered for many years. When she discussed it with him, he had told her that if it was his child, he would not want the vaccination, and he could not tell her the vaccine was perfect. However, later in the interview she said of her son: *"Three days before [he] went in to hospital with measles, he was covered in measles. He had his injections to prevent it. He ended up with measles in hospital, but the kids who didn't have any injections at all didn't get nothing."* This indicates a possible lack of understanding about the nature of the MMR vaccination and what it protects against, which then may have contributed to a sense of fatalism when the family was affected by measles.

This again highlights the deep importance of trusted relationships in providing health knowledge and informing health decisions. It also illustrates that, at least some of the time, failure to ensure (some) childhood immunisations may be the result of considered decision-making, linked with cultural beliefs, rather than due to lack of awareness, a failure to take such matters seriously or difficulties in accessing services.

Mobile outreach services

The mobile playbus in Brighton was cited several times as a good thing; interviewees were particularly positive about the fact that, with the playbus, health visitors came to sites and talking to everyone, not just to mothers. Interviewees told us they would like to see this same approach taken in West Sussex.

"The health visitors [on the playbus in Brighton] will say 'do you need a dentist, do you need a doctor, do you need any kind of help, have you got babies, do your babies need their needles?' ... they have to come and check everybody, even if you don't have children ... In West Sussex they don't do that at all - you have to register your kid with a doctor before they know you're there."

Another woman told us about her son's health visitor, whom she'd met at the Brighton transit site. *"She's great. She makes all the appointments. She keeps on top of everything for me."*

She was fighting with the council to get me seen, so that [my son] could get the help he needed. When you pull into camps they come out for health checks. I met her last year. She comes to see me every Wednesday. She is really good, I can't fault her."

Stakeholders at the seminar in July told us that there were, indeed playbuses in West Sussex, as well as in Brighton, and there was some disappointment that interviewees seemed unaware of this. However, we were unable to find any information about the playbus(es) on the WSCC or other websites, which suggests that publicity needs to be improved.

In 2007 the West Sussex Purple Bus mobile youth centre was part of a small-scale, time-limited project to reach out to Gypsies and Travellers. It visited three sites three times, with different organisations on board. The aim was to provide information to young people about services available. As a result, better contact was established between adult education services and the Gypsy and Traveller community, and a small literacy group was set up at the Community House in Denham Road, Burgess Hill⁵⁷.

OPM was unable to collect systematic information about mobile outreach and health promotion services working with Gypsies and Travellers in West Sussex. We were informed that Action in Rural Sussex, and some children's centres, ran mobile services that might, or might not, work with Gypsies and Travellers. Even if such services do exist in West Sussex, it would seem that they are not particularly well co-ordinated or publicised.

Health visiting and health promotion

Health visitors told us that they believed new arrangements for health visiting meant they now had much less contact with mothers and young children than previously, and as a result did not have enough time and contact to build up trusting relationships with the Gypsies and Travellers they worked with. Whereas previously the norm had been for health visitors to see pregnant women once before the birth, and then see mothers and babies just after birth, twice more before six weeks, at 12 weeks, eight months and a year, they now see them at far less frequent intervals. This reduced amount of contact has resulted in fewer opportunities for informal health promotion. When visiting a mother and baby in a Gypsy or Traveller family, health visitors told us that previously they would often encounter other family members, such as the new mother's sisters visiting with their own children – such visits and extended family support are common in the Gypsy and Traveller community. Health visitors felt that through getting to know the wider family, they were able to develop better relationships of trust, and talk informally to wider family members about their children's health, give informal health education, or gently remind people about matters such as diet, nutrition and immunisations. Now, however, health visitors believe that they do not see their clients frequently enough to build these relationships with wider family members, and be trusted enough to discuss health education matters in this informal way.

Although these new arrangements, with fewer visits as 'standard', apply to everyone, health visitors said they thought they impacted disproportionately on Gypsies and Travellers, because of their lack of access to health information from other sources, such as leaflets and books, and because of the very great significance placed by Gypsies and Travellers on individual, trusting relationships as sources of health information.

⁵⁷ Sussex Traveller Action Group, powerpoint presentation, March 2009

Health visitors we spoke to attributed these changes to a new health visiting contract commissioned by the PCT. However, NHS West Sussex takes a 'commissioning for outcomes' approach, and the commissioning arrangements do allow providers to exercise discretion, and visit more than the 'standard' number of times where they judge this to be necessary. Thus, current commissioning arrangements should not preclude additional visits to Gypsy and Traveller families, where this can be justified by the health visitor, and in line with an assessment of need and risk, and an agreed and personalised care and support plan. However, there is an underlying problem with capacity, as the health visiting service in West Sussex has found it difficult to recruit in recent years. It may well be that local managers are managing these capacity constraints by telling health visitors to apply the 'standard' arrangements, and not encouraging or allowing them to provide an increased number of visits for Gypsy and Traveller families, or others who might require more intensive support.

It was a matter of serious concern to several of the stakeholders we spoke to that health promotion work is not being explicitly commissioned, and is therefore 'getting lost' in the new commissioning arrangements.

Men's health

Matthews says that "it is particularly common for Traveller men to be stoical about their health" and "the experience of the Sussex Traveller Health Project is that men are reluctant to come forward to discuss health issues, but may seek information through the services that their partners access."⁵⁸

The Sheffield University team reported that men, in particular, appeared to dismiss minor health complaints as insignificant, reflecting the culturally ingrained stoicism within the Gypsy and Traveller community.

Our interviews with Gypsies and Travellers confirmed the impression that Gypsy and Traveller men don't go to the doctor, or present very late, and prefer to self-medicate rather than seek medical advice. One woman told us: "*Some men don't like going to the doctors, they'd rather stay at home and have an Oxo and a bit of pepper in it to make them better. If they've got flu they drink a cup of whiskey and lay in bed for a week. They try and do their own thing.*"

Men were described as 'shy' or 'embarrassed' to go to doctors, especially about 'personal' matters: "*they might tell my mum – they'll tell their own wife, but they still won't go to a doctor.*"

Women we spoke to said that, despite men's reluctance to seek help for their own health or to discuss women's health, their male partners would attend children's appointments, and would drive them and their children to appointments.

One of the men we spoke to told us that his attitude to health and health interventions had changed significantly since his own multiple health problems had developed. His view now was that: "*anything I can do that might make me better, I'll try it*" whereas previously he had

⁵⁸ *The Health of Gypsies and Travellers in the UK*, Matthews, Race Equality Foundation, Better Health Briefing Paper, 2008

rarely gone to the doctor, and had been far less open to preventative health measures such as scans, blood tests and health advice.

Another man we interviewed was highly resistant to seeing an optician, even though his eyesight was severely failing. Instead, he used a pair of reading glasses with no arms that he had found in the back of a second-hand car. His adult children perceived this to be as much a generational issue as a gender one, and pointed out that their mother was also resistant to seeking a hearing test.

One interviewee expressed concern about her young sons - who have significant health problems - when they grow up. She was worried that if they are travelling as adults "*they will think they cannot be bothered*" to get medical help. She thought that they would be far more likely to seek help and treatment as adults if they are living somewhere settled.

The Gypsies and Travellers we spoke to had few suggestions for how health services could become more accessible to men, although one woman suggested that men would rather see a male doctor about personal matters, and not a woman doctor or nurse. The response of others implied that the issue was a deep-rooted cultural one, and that there are not necessarily any obvious or easy steps that services can take to become more accessible: "*I don't think it's the accessibility, it's just the way the men are. They'll hang on as long as they can, and then they'll go.*"

Health and accommodation status

An important finding from the Sheffield University report was that, for Gypsies and Travellers, living in a house is associated with long term illness, poorer health status and anxiety. People who rarely travel had the poorest health. However, it is not clear whether living in a house has a negative impact on Gypsies' and Travellers' health, or whether those with the poorest health decide not to travel. Parry reports: "In the Gypsies and Travellers group, we found a relationship between health, accommodation type and travelling pattern. However, it is not possible from these data to determine whether accommodation and travelling patterns have an effect on health, or vice versa. Those with poorer health status may choose or be constrained to live in a house or travel rarely. On the other hand, living in a house or on a council site, and travelling rarely, may have a negative effect on health."⁵⁹

Parry also says: "Gypsies and Travellers with long-term illness are more likely to be living in a trailer on a council site or in a house than on a private site or on empty land. The same pattern is found for the EQ-5D tariff scores⁶⁰, with those on private sites or empty land reporting better health status. Other physical health problems did not differ significantly by accommodation."

Impact of accommodation on health

We asked interviewees what they thought were the major factors impacting on Gypsies' and Travellers' health. Not surprisingly, travelling and accommodation status figured highly, and

⁵⁹ *Research report: Health status of Gypsies and Travellers in England*, Parry et al, JECH, 2007

⁶⁰ EQ-5D is a standard and widely used instrument for measuring health status and health outcomes

was a subject on which people expressed strong views. Virtually all the people we spoke to told us spontaneously (without prompting) that the quality of accommodation and living environment was a huge factor in the health of Gypsies and Travellers. Our interviews found both positive and negative aspects associated with each different kind of accommodation situation, in terms of their impact on people's health, wellbeing and access to services.

Several people commented on the recent government announcements that grant funding for development of Gypsy and Traveller sites had been ended. One said: *"It said it in the front of the newspaper, since this new government come in: 'Gypsies' easy days are gone'. But what's easy about this life?"*

A strong theme that emerged was the need for children to be able to play safely, outdoors and in the fresh air; the ability to spend time outdoors was strongly associated with concepts of good health. The interviews revealed that the wellbeing of one's children was a major factor in Gypsies' and Travellers' decision-making about what kind of accommodation and travelling arrangements to adopt. In several cases, the perceived benefits to the family's children had been the main reason for making a transition from site to settled housing, or from settled housing to site.

Travelling and living on the roadside

Many people told us that the stress of being 'sectioned' and moved on had a negative impact on health. Even people who had not travelled for many years spoke passionately about this.

"I think it makes a lot of difference. When they're off the road they ain't got the police to worry them, they're in one place, in a house or on a site. If you're settled in one place, it's better for you."

A woman currently travelling and taking anti-depressants told us: *"Peace of mind goes a long way, it helps more than any medication. If you can go to bed at night, and get up of a morning and not get stressed and weared out and pushed over the boat, it goes a long, long way. But you can't have that when you're Travellers."*

"You're panicking when you're moving. You're thinking 'they're gonna take my home.' Your home is everything you've got."

One woman spoke of being told by the police to move on, and to drive her trailer containing her children that night, when she had already taken sleeping pills. Her request to wait until the next day as it was dangerous to drive having taken the sleeping pills was refused.

Another told us about the death of her cousin's five year old son, on an unauthorised site at Stanmer Park, Brighton several years ago. The family had been given an hour to move, and in the rush and flurry of activity to get moving, the child had jumped on a trailer, fallen underneath without being seen, and been crushed by the trailer. Her view was *"he was killed, literally, because they only had an hour to leave."*

Making and keeping appointments

People spoke of the difficulty of both making and keeping medical appointments whilst travelling. *"If you're on the side of the road, your phone goes flat. You've got no electricity to charge your phone. You're bodily ill, but you've got to stand in a phone box to ring these emergency numbers."*

"Getting moved around, you can't keep on top of it. You can't go to your doctor's appointments...How can you make kids' appointments, or make appointments for our own health, when you don't even know if you're going to be here. We may be pulled two hundred miles away."

Some also associated travelling with late diagnosis of medical conditions. The interviewee with an adult brother with autism said that this had not been diagnosed until he was 18, because her parents had been travelling throughout his childhood. She thought that if he had been diagnosed earlier, then perhaps he could have had more help, and now be better able to function independently rather than being so dependent on their parents.

Cleanliness and hygiene

People told us that maintaining good hygiene and cleanliness were more difficult when travelling, and some thought this impacted on health: *"They take urns of water, but it's not always the best way of cooking, cleaning, washing yourself."*

Settled housing / bricks and mortar

Stress, anxiety and depression

People who were living in housing, or had previously done so, also told us about their experiences of stress and depression.

One interviewee told us she suffered from "a nerve disorder" [anxiety]. She had moved several times between sites and settled housing, and was now in a house. *"To be honest since I moved from the site into a house I thought I was doing the right thing, but since I've been in the house I've been worse in myself for health reasons."* When asked to explain, she continued: *"I get nervous...I think it was after having freedom on the site for them few years and then moving in, back to a house, it's just I feel claustrophobic and I think that's what's making me a bit worse than I used to be."*

She contrasted the sense of freedom she felt on a site, with her feelings living in a house: *"sometimes I visit my sister up there [on a site] ...and we spend the whole day and I feel lovely, I feel fine, you know, and then I get back in and I feel down, really down. Sometimes I sit and cry."* This interviewee was now trying to see if she could move back to a site: *"As much as I wanted to leave the site to get settled for the kids' sake, that's how much I would like to go back, because when it comes to your health, you've got to do what's best for you."*

One woman told us she had great difficulty sleeping, as she had been housed in housing association accommodation on very noisy main roads. There was a lot of nuisance and low level harassment, with people ringing on the buzzers late at night. She was being treated for depression and anxiety, and said of this environment: *"It's not doing my depression any good...My son does not like it here, there's no garden, it's too dangerous to let him outside. I have to take him to my mum's so he can play."* Her son's school had contacted her because they had noticed he was very tired, and had dark rings around his eyes.

Another woman had described significant hardships experienced whilst travelling, and spoken about the negative impact on her health, that of her family, and their ability to access services. But when asked whether she would want to live in a house, she was unequivocal:

"It's like taking a fish out of water ... It [travelling] is not something we choose to do, it's something that we are."

The interviews appear to confirm that living in settled housing can either trigger or exacerbate depression and anxiety, amongst Gypsies and Travellers.

Effect on children's health and wellbeing

The effect that their accommodation had on their children's health and wellbeing was a recurring theme. One woman told us that she had previously lived in a house with her family, but decided to move back to a permanent site *"for the kids, really...it's safer."* She explained that there had been a park across from their house, but when they had taken their baby son there, they were unable to let him play on the grass because they had found needles, and this had prompted them to want to move. *"Here [on the site] you know your environment, you know it's safe, you know your kids are going to be safe, because everyone looks out for each other's health."*

Positive aspects of living in settled accommodation

One young woman whose family had moved from a site to a house told us *"healthy just means not having sicknesses, like coughs and colds. We have less of those now that we live in the house."*

Authorised sites

People spoke of the difficulty of getting a place on an authorised site, saying that waiting lists were very long, and some sites seemed to be *"for families only"* meaning for relatives of those already living at the site. Others said *"you wait ten, fifteen years"* for a place on a permanent site, and *"you won't get a plot for [the authorised sites at] Burgess Hill or Haywards Heath - there's waiting lists."* Some people who were travelling expressed a clear desire to have a plot on an authorised site, despite all the concerns and drawbacks articulated. One said she'd *"love"* to have a place on a permanent site. Another said *"that's the main concern when it comes to health, is that you need somewhere permanent."*

Cleanliness and hygiene

People told us about the lack of access to clean water, and the lack of proper sewerage on sites. They spoke of the lack of facilities for washing and showering.

A young person whose family moved from a site to a house said: *"We are better here, and we have less coughs and colds. It's because of the water supply – on the site it was dirty. We had to drink water from bottles. And generally the site was dirty. There were rats."*

"And we can shower when we need to. Before we had to use the local leisure centre showers, and pay every time we wanted to use them for the bus down there and for the entry. It was really far."

Other people also spoke about rats on sites. Although the council does take measures to deal with them, bringing in pest control services, several Gypsies and Travellers we spoke to were unhappy that the problem is such a persistent one.

Safety

Many people expressed concerns about safety on sites, especially in relation to their children. For example, one interviewee was worried about a site situated on a busy road, used by lots of lorries, and without any footpath. Interviewees also pointed out that the site lacked lighting, and that the fencing on the site had lots of holes and gaps, through which children could fall or crawl, and then find themselves in danger.

A young woman whose family had moved from a site to a house told us: *"You trip over on the site more 'cos there are things left on the ground, so you hurt yourself like that. We don't have that anymore."*

As discussed in the section on children's health above, there is evidence that accident rates are higher amongst Gypsy and Traveller children compared to other children, and poor quality and hazardous sites have been identified as a factor⁶¹.

Several people cited the lack of safe or dedicated play areas for children, on both transit and permanent sites. At one site, interviewees thought the facilities were generally good, but that the lack of a children's play area had an impact on health, because they believed it was important for children to be able to run about and exercise. Another interviewee told us that her children had experienced bullying, abuse and discrimination when playing in public parks.

Some people told us that arguments between families on sites were often triggered by children playing, for example because children were being too noisy, or playing too close to other people's caravans. They thought rows on site caused stress and bad feelings, and were not conducive to good mental health. They traced these rows back to the lack of adequate children's play facilities.

Cold and lack of heating

Some people told us that being cold was a problem, and affected their health. One woman with osteo-arthritis living on a permanent site told us: *"In the winter I get cold, and I'm terrible with the cold, shaking with the cold, and the cold makes it worse, with this [knee] and with that warm we've had, I was lovely. I never had one pain, with the heat."*

Another interviewee said of her parents in their 60s, who live on a permanent site *"they survive in the summer, but as soon as you get to winter, it's the cold that gets to them."*

Stakeholders told us that if older Travellers on permanent sites are receiving pension credits, then they should also receive the winter fuel allowance. However, for people who are travelling, their ability to claim winter fuel allowance will depend on whether they have a permanent address, as transit site addresses are too short-term to be used for this purpose.

Gypsies and Travellers may face higher than average heating costs, both because of the design of their caravans (e.g. cavity wall insulation is not possible for most mobile homes) and also because they are often dependent on calor gas, which is expensive. One stakeholder told us: *"I know that the cost of calor gas, especially if someone suffers with a health issue that means they have low mobility or circulation issues, can be very costly during the warmer months let alone the colder months. They often have additional heaters."*

⁶¹ *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

Stakeholders told us that in their experience the cold affects families with children, as well as older people: *"we often have adults with young families asking if there is any support for the cost of heating, (work can be seasonal for some Travellers). They are often referred to the children's services to ask for assistance, not many like or probably take up this advice."*

Private sites

Interviewees told us that they knew people on private sites, and cited better security, having your own privacy, and having your own toilet, as advantages of private sites.

Mental health

Parry⁶² found that Gypsies and Travellers were over twice as likely to be depressed, and almost three times as likely to suffer from anxiety, as others. The research found that Gypsies and Travellers experienced poorer mental health, even compared to other socially deprived groups or other ethnic minorities. Women were more likely than men to have experienced mental health problems. The EHRC report speculates that the stresses caused by accommodation problems, unemployment, racism and discrimination by services and from the public, and bereavement, may all be contributory factors.

The EHRC report says "for women, long-term mental health difficulties can result from feeling trapped on a site where no-one would want to live." However, moving into a house is also associated with depression and anxiety for many Gypsies and Travellers, and may be a result of isolation, loss of community and experiences of discrimination.

Mental health was a major theme in our interviews. Several people reported severe and chronic mental health difficulties including depression, anxiety, paranoia, and possible bipolar disorder. Several also told us of family members with mental health problems. Many people made direct links between their current living and accommodation arrangements, and their mental health. Others – including those who were not experiencing poor mental health themselves - described the many stresses and uncertainties associated with travelling, and acknowledged the likelihood that this would impact on mental health.

In addition to accommodation and living arrangements, and the pressures associated with travelling, there appear to be a myriad of further issues that contribute to poor mental health amongst Gypsies and Travellers, including social isolation, the experience of racism and discrimination, domestic abuse, and frustration and a feeling of 'having no control' over one's life or living situation⁶³. Interestingly, none of the people we interviewed cited poverty, debt or financial difficulties as factors affecting their mental health.

Another factor is seeing one's children being bullied and called racist names: *"It gets me down. I feel run down about it, and I think they're spotlessly clean, we were brought up*

⁶² *The Health Status of Gypsies and Travellers*, report to Department of Health, Parry et al, University of Sheffield, 2004

⁶³ For example, see report of Gypsy and Traveller Mental Health Event, Haywards Heath, Friends, Families and Travellers, 25 June 2009

clean. As you can see, it's not filthy in here, the kids are not filthy and it upsets me when they get called dirty stinky pikeys and stuff. It's not fair."

The experience of racism had also affected the interviewee's children: *"the girls wasn't happy in school because they was being called pikey and they was coming home miserable and sometimes they wasn't eating their tea and they didn't want to go back to school because of it and it was getting me down because of it."*

For most people, their GP had been the starting point for seeking treatment and support for mental health problems. Some were taking medication, and some had been referred to see mental health support workers or counsellors.

Despite a surprising degree of openness with us, there remains a great deal of fear of mental illness, and of mental health services within the Gypsy and Traveller community. The adult family of a woman who suffered from depression and anxiety and had had "a breakdown" told us that she had been afraid that if she spoke to anyone about it, she would be "locked up". Before her own breakdown, this woman's children told us that their mother's attitude to mental health problems was that you should "pull yourself out of it", and her lack of understanding had contributed to her fear of engaging with mental health services once her own problems emerged.

Use of alcohol and drugs

Matthews reports that "alcohol consumption is often used as a coping strategy." Matthews also says "drug use among traveller young people is widely reported and feared by Traveller elders...there is little research into this subject [of substance misuse] in the UK. However anecdotal evidence suggests that it is on the increase, in line with other communities, particularly where families have been housed on run-down housing estates, or where unemployment and depression are common."⁶⁴

We decided not to ask people directly about drug and alcohol use, as after discussion with FFT we concluded that this would be too insensitive and risk alienating people. None of the interviewees volunteered information about their own drug or alcohol use, or that of family members or others close to them.

Access and use of GP services

Many of the Gypsies and Travellers we spoke to reported very positive relationships with their GPs. Some had been with the same GP for many years, sometimes since childhood, and it was apparent that a personal relationship with the doctor is highly valued. Comments included *"He's a lovely man. He said 'I'd do anything for you, whatsoever'"* and *"My old doctor was pretty good, you'd walk in there, nine times out of 10 you didn't need an appointment. Same for my mum and dad. He was brilliant. When my nan died, her own doctor wouldn't come out to register her death that night, this doctor came out to do it, that's how nice he was."*

⁶⁴ *The Health of Gypsies and Travellers in the UK*, Matthews, Race Equality Foundation, Better Health Briefing Paper, 2008

However, even people who reported good relationships with their own doctors identified the difficulties that Gypsies and Travellers have in accessing GP services when travelling as a major issue impacting on the health of Gypsies and Travellers. In particular, Gypsies and Travellers highlighted variations in the approaches taken by different GP surgeries when registering patients, including temporary patients. Some GP practices insist on seeing three forms of identification - such as a passport, utility bill, or driving licence. Others are more flexible, and will see Gypsies and Travellers who cannot provide three forms of ID. Interviewees pointed out that many Gypsies and Travellers don't have passports, and those who are travelling are unlikely to have utility bills.

When this issue was discussed at the stakeholder workshop, it was suggested that a wider range of forms of identification should be accepted by GP practices, including, for example, a letter from the site manager of an authorised local authority site confirming name and address.

Although many Primary Care Trusts in England have issued guidance to GP practices advising them to implement stringent identity checks before registering patients, there is, in fact, no legal requirement to do so. The Department of Health recently confirmed that: "General practices are not required to carry out any mandatory checks relating to a person's identity or their address...the nature and extent of any such validation is for the individual general practice to determine"⁶⁵. A recent piece of research by the chair of the Royal College of GPs' health and inequalities commission found that GP practices in a quarter of Primary Care Trust areas had been advised to implement such identity checks. The committee chair, Dr Angela Jones, pointed out that many people do not have utility bills, and said "the most disadvantaged are the least likely to have the documents being demanded."⁶⁶

Not knowing whether they would be able to find a GP practice willing to see them when travelling to a new area created a great deal of uncertainty for Gypsies and Travellers. In response to this uncertainty, Gypsies and Travellers ended up taking precautionary measures, especially in relation to their children's health. Some mothers reported stocking up on Piriton (anti-histamine) and Calpol (liquid paracetamol) for their children, in case they could not see a doctor in a new town. Another, whose children had cystic fibrosis, told us that she routinely travelled with 3 months' supply of medicines, in case she could not obtain these whilst travelling. Another interviewee told us that if travelling Gypsies are not registered with a GP, they are more likely to go straight to A&E.

Receptionists

Several interviewees identified difficulties with receptionists acting as gatekeepers, as a barrier to Gypsies' and Travellers' ability to access primary care.

"If you say you've got no fixed abode, when they hear that they just have got no interest. It's not the doctors, it's the receptionists."

"One of them [receptionists] told me before: 'you don't look sick'."

"I'm sick of your lot' how many times have you heard that? It's usually the receptionists. It's not the dentists and doctors themselves, it's the receptionists."

⁶⁵ *Inequality fear over patient ID guidance*, Health Service Journal, 19 August 2010

⁶⁶ Health Service Journal, *ibid*

At the stakeholder workshop, participants acknowledged that some reception staff in GP and dental practices could be rude and abrupt, and this was likely to be particularly off-putting to Gypsies and Travellers. It was pointed out that receptionists were sometimes explicitly required by their employers to take on a 'gatekeeper' role, so as to manage workload in relation to the capacity of the practice. Stakeholders discussed the fact that receptionists were not always invited or required to take part in training that was available for clinical staff, such as cultural awareness training about Gypsies' and Travellers' culture and needs. There was a strong belief amongst stakeholders that any such cultural awareness training should be available to all GP practice staff – not only clinicians – and that in some cases (depending on the nature and location of the practice) reception staff should be required to attend.

Alternative ways of accessing primary care

Some of the Gypsies and Travellers we spoke to had used NHS walk in centres in Brighton and Crawley, as an alternative way of accessing primary health care. Generally the walk in centre model had seemed to work well for them. Some of the Gypsies and Travellers we spoke to expressed a desire to see a walk in centre in Burgess Hill. Some people had used the Morley Street clinic in Brighton, which is a clinic for homeless people. However, several disliked having to take their children there, as they found it dirty, and worried about finding needles on the premises and in the toilets. Although they appreciated the accessibility of the service, they did not all think it was an appropriate place for them to take their children.

A number of interviewees had suggestions for the way in which access to GP services for Gypsies and Travellers could be improved:

"It would be silly to say if they had a special clinic in every district, but if there was a lot of Gypsies in one district, it would make sense, or a district where they know a lot of Travellers go over the summer holidays with their kids, it would make sense...just somewhere they can go without too many questions, when they're already signed up with someone..."

"When they travel round, make it more accessible for them to be able to walk into a clinic, without 'the usual' getting asked for lots of ID, who you're registered with, where you're registered with, then you ask to be registered and they don't give you an answer there and then, you need to wait and they write to you. They [Gypsies] don't want that, they need to be able to go in and see a doctor."

Potential of patient-held health records

At the stakeholder workshop, the idea of Gypsies and Travellers having patient-held records, which they could take with them as they travel, received strong interest, with some stakeholders aware that this was being piloted in Hastings (and other parts of England) as part of the Department of Health funded Pacesetters Programme. However, there are concerns about the degree of confidentiality afforded by this approach, with, for example, a husband having easy access to a wife's record, if it is in the same, small caravan. This is a particular concern for someone experiencing domestic violence, for example, who may wish to be able to discuss this in confidence with health professionals, but would be at risk if her partner discovered that she had done so. Low literacy levels mean that some Gypsies and Travellers may be wary about information being recorded about them in their patient-held record, that they cannot read for themselves.

The evidence to date from the evaluation of the Pacesetters Programme is inconclusive. The pilot project was to design, develop and implement a Personal Adult Health Record (PAHR) for Gypsies and Travellers in selected areas in the West Midlands and South East Coast strategic health authorities. The evaluation report for the Department of Health⁶⁷ describes the processes involved in setting up and implementing the project, and gives an analysis of how and why these took much longer than initially planned. The report says that: “By February 2010 there was a variation in numbers of records distributed to Gypsies and Travellers in different Trusts. Most Trusts had not yet distributed any records, but where this has commenced...there are reports that Gypsies and Travellers have produced them at GP practices. There has not yet been an audit of record use in terms of baseline information entered into the records or level of use by health professionals. It is therefore too early to evaluate the use and impact of the Personal Adult Health Record.”

The evaluation also looked at the literature, and was unable to find robust evidence in support of such approaches. “Various versions of Patient Held Records had been in existence in individual Trusts over the past couple of decades, but there has been little evidence of project management of their implementation or evaluation of their use and effectiveness.” The report says that a literature review looking at interventions to enhance the health promotion evidence base on Gypsies and Travellers published in 2005 revealed that “although many studies were found to have recommended the use of hand held records, there were few descriptions of pilot schemes to implement the intervention and a dearth of formal evaluations.”

Another model of interest is that of online, web-based patient-held health records offered through private companies such as Google Health and Microsoft HealthVault, or through the NHS HealthSpace initiative. These enable people to set up an account for free, and then store, manage and organise their own health information. Health information can be logged by the patient, and with some products (e.g. Google Health), information can also be imported from authorised partners, such as (in the USA) some hospitals and pharmacies. Gypsies and Travellers might benefit from being able to produce and instantly access, via a computer, up-to-date health records and show these to GPs and other health professionals and authorities, wherever they are. However, people with low levels of literacy, health knowledge and IT skills may well lack the confidence, ability and motivation to set up and maintain such records. If online patient-held records are seen as potentially most beneficial to those who are travelling, then it must be remembered that these are the very people who are most likely to have intermittent and unreliable access to electricity, so that even viewing and maintaining an online health record may be difficult, and the model depends on the record being constantly kept up-to-date. Furthermore, despite assurances that online health records can only be accessed by the patient or with their consent, there may be issues of trust and of confidence in data security, and a wariness of committing one’s personal and confidential details to ‘cyberspace’.

The Conservative party when in opposition expressed interest in the potential of online patient-held health records as a substitute for the NHS electronic patient record database⁶⁸. In the USA, Google Health has been operating a beta test system since 2008, and has

⁶⁷ *Pacesetters Programme Gypsy, Roma and Travellers core strand, Evaluation Report for the Department of Health*, Van Cleemput et al, University of Sheffield, April 2010

⁶⁸ *Cameron: Patients should store health records with Google or Microsoft*, The Guardian, 6 July 2009

partnerships with major pharmacy chains enabling patients to import their prescription history and details into their own online record. In the UK, online patient-held health records will depend for their value and effectiveness on the willingness of pharmacists, GPs, NHS bodies and other healthcare providers contracted by the NHS, to all agree to export information to patients' records on request, so that the record can be full and maintained. This, in turn, will require GP practices in particular (many of which do not even communicate with patients by email)⁶⁹ and other health providers to develop their own IT skills and systems. Major questions remain about whether the model developed in the UK will be for online patient-held records stored through third party suppliers to *complement* official NHS patient records, or to *replace* them. It would seem that the systems currently available in the UK are still too immature for their benefit to Gypsies and Travellers to be tested and evaluated. However, this is an area worth further consideration in future, especially if and when GPs, NHS providers and other providers commissioned by the NHS are able and willing to export patient information directly into online records.

Access and use of dental services

There is little literature and research evidence on the dental and oral health needs of Gypsies and Travellers. The EHRC report⁷⁰ cites two studies from 1997 that found Gypsies and Travellers were significantly disadvantaged in accessing dental care and oral health, due to the inability to obtain regular check-ups and ongoing treatment. Despite a lack of more recent evidence, the EHRC say that casework carried out by the report's authors and information from various GTAAs implies Gypsies' and Travellers' access to preventative dental services has got worse in recent years, and that "the general decline in access to NHS dentists over the past few years is likely to have an even greater impact on highly mobile families."

The Gypsies and Travellers we spoke to who were registered with a dentist reported being happy with the service and dental care they had received. However, several told us that they wanted to be registered, but had not been able to find an NHS dentist where they could register. One woman based in Burgess Hill told us *"I never use a dentist in West Sussex because they won't accept NHS, so I have to go to Brighton instead."*

Another woman from Burgess Hill told us that she and her family had been registered with a dentist locally *"but we got a letter about six months ago saying our family was being taken off the list because they had over-estimated their patients. It wasn't just us, it was lots of people. We haven't been able to find another NHS dentist, but we're on some waiting lists and they'll ring us when they have places."*

Late presentation

Another theme that emerged from the interviews was late presentation, with a tendency to seek dental treatment only when in pain: *"I don't really go to the dentist...I had my teeth out once, I was in pain."* The adult children in one family told us that their father would not go to

⁶⁹ A King's Fund Research paper for the inquiry into the quality of general practice in England, *A Rapid Review of Access to Care*, the King's Fund, 2010 cites a 2007 study which found that 11 per cent of people in the UK said they were able to communicate with their GP practice by email.

⁷⁰ *Inequalities Experienced by Gypsy and Traveller Communities: a review*, EHRC, 2009

the dentist, even though he 'needs teeth' as he had lost his natural teeth. They pointed out that he was not afraid of the dentist and had been previously, but would not go now, and because he has no teeth "*people don't want to talk to him*". They suggested that perhaps their father would be willing to see a dentist who came out to visit him.

One woman told us about having a painful abscess whilst in Haywards Heath, but despite trying numerous dentists over a period of several days, she could not find one that would treat her, as she did not live in the area and was not registered with a dentist locally. The hospital also told her they could not treat her, and that she should see a dentist instead. Despite asking the dental surgeries for treatment as an emergency, she was instead given phone numbers, and eventually found an emergency dentist, who referred her straight to hospital. "*My face was swelled up like a balloon... They had to do an emergency operation... I came out of hospital, and they made us move [on from the site], even though I had to go back. They wanted to send bits off to test it. I never did go back to see what the results were, because we had to move out of the area.*"

As with GPs, some interviewees thought that dentists' receptionists could be rude, and at times display prejudice against Gypsies and Travellers, and prevent them from accessing services.

Several stakeholders told us that, in the course of their work, they see young children from Gypsy and Traveller communities with very poor teeth. Some children of primary school age or younger have required tooth removal under general anaesthetic, due to the degree of decay. Health visitors told us that they have found a lack of awareness of good dental health amongst Gypsies and Travellers. For example, young children may be given bottles of sweet fizzy drinks or babies' bottles with sugary drinks. Young children are also given Calpol (liquid paracetamol, containing sugar) on dummies or diluted in bottles. Children's diet and oral health was linked by stakeholders to the wider socio-economic conditions and cultural expectations within the Gypsy and Traveller community. For example, when a father comes home tired at the end of the day after work, children are expected to be quiet and accommodate his needs. In a small living space, such as a caravan, crying or fractious children may be given sweets or a sweet drink as the quickest and easiest way to get them to be quiet. Stakeholders pointed out that there was a lack of commissioning for oral health promotion and prevention work, and that this was a major gap. One stakeholder expressed frustration that: "*tooth decay is a preventable disease – why isn't it being prevented?*"

One stakeholder told about changes in NHS West Sussex's commissioning for oral health and dental services, which took effect in April 2010, and the detrimental impact she thought these changes were having on Gypsies' and Travellers' ability to access dentistry, as they can no longer access dentistry through Community Personal Dental Services. She thought this would have a major negative impact on the oral health of Gypsies and Travellers, and contrasted the approach in West Sussex with that taken elsewhere.

Access and use of hospital services

Some of the Gypsies and Travellers we spoke to reported very positive experiences of using hospitals. People who had used specialist services or received long term treatment seemed to be the most positive, and appeared to have developed trusting relationships with hospital staff. Some hospitals that people were most positive about were outside West Sussex; for

example the hospital where the interviewee with brain tumours had had surgery, and the hospital where the children with cystic fibrosis received care.

Within Sussex, people had generally positive views about the Princess Royal Hospital in Haywards Heath, and the Royal Sussex County Hospital in Brighton. One woman told us: *“I had my son in Brighton. I got good care. I was in hospital for two weeks afterwards, they would not let me leave. It wasn't to do with the baby, it was to do with me. They made sure I was a hundred per cent before they let me out.”*

Hospital staff's attitudes to visitors and cultural awareness were important, and in particular an understanding of the importance of extended family and friends in providing support to Gypsies and Travellers in hospital.

“They [Royal Sussex County Hospital] weren't funny about visitors or anything. Because when a Gypsy or Traveller woman has a baby, if there were 50 caravans, every woman in those caravans would go up and see the lady who had the baby, and bring presents and balloons. Some hospitals can't handle it, but Brighton don't take any notice.”

Another interviewee told us that staff in hospitals and doctors should recognise that families will want to be involved when someone visits hospital or a doctor. She felt that she was a strong advocate for her mother, asking lots of questions and speaking for her, but that many medical staff did not understand their culture:

“When I went up to the hospital with Mum on Saturday and I just demanded that I want something done. That doctor was lovely, and was obviously used to Travellers with the daughter overtaking [taking over] everything, cos that's what they're like. We went to the doctors here and I was talking and I felt she was looking at me enough to say, ‘what are you doing?’ Mum was shy and saying ‘no, sshh’ [about her depression] and the doctor must've thought it was private and I shouldn't have been there, but if she knew what the Travelling community was like, she would have respected me more.”

Referrals and appointments

An issue raised by both Gypsies and Travellers and stakeholders was the lack of continuity for people waiting for a hospital appointment following referral. If someone travels to a new place whilst waiting for such an appointment, they have to start again ‘at the bottom of the list’ in the new area, meaning the waiting time for an appointment is lengthened. People were particularly concerned about this delay when waiting for appointments for their children. Gypsies and Travellers pointed out that sometimes the move to a new area was an enforced one, caused by being moved on by police or threatened with enforcement action. Gypsies and Travellers wondered whether people who had been waiting for a hospital referral could somehow transfer their place on the waiting list to the new area when they moved, in recognition of the time already spent waiting.

Under the NHS ‘Choose and Book’ system, patients can choose which hospital or clinic they want to attend for any outpatient appointment, and also choose the date and time of their appointment. Anyone who has a GP referral can make or change their outpatient appointment online or by telephone, including to a different hospital or clinic in a different part of the country. However, although providing greater flexibility and choice for patients generally, ‘Choose and Book’ does not appear to offer a solution to the difficulties articulated by Gypsies and Travellers that we interviewed. The system is predicated on patients being able to predict that they will be able to attend an appointment on a given date and time and in a given location – all chosen by them. But for Gypsies and Travellers who are travelling, a

major issue is the *unpredictability* of their lives - not knowing whether and when they will be moved on, and not knowing in advance where they will move on to next. Furthermore, to use 'Choose and Book' directly (rather than via GPs), patients again require: literacy; IT skills; to have to hand and be able to read their original GP referral letter, reference number and a password; and the knowledge and confidence to make choices about which healthcare provider to use – all conditions which are unlikely to obtain for a high proportion of Gypsies and Travellers.

Interviewees also said sometimes appointments were missed because they did not receive their appointment notifications, due to being moved on. Some interviewees felt it was unfair that Gypsies and Travellers had a reputation for missing appointments, when sometimes this was as a result of being moved on, and not something they had control over. Stakeholders told us that it was difficult, as if Gypsies and Travellers did not inform them that they were going travelling or being moved on, then they could not be expected to know. Some hospital services now text people to tell them or remind them of appointments, and some interviewees seemed to find this helpful.

As with non-Gypsies, just a few incidents can leave people with a very strong impression, either positive or negative, of a hospital. One person had a negative view of Worthing Hospital, saying it was “*shit*” and “*wasn't all that hot*”. The reasons for this were that her sister had been turned away when in labour, and had to go to Brighton instead, when “*the baby could have come at any time*”, and also that she had cut her hand about 10 years ago, and Worthing hospital would not stitch it, saying it would heal on its own. As, within the Gypsy and Traveller community, friends and family are a key source of information about health services, usually through word-of-mouth, these impressions can easily spread and influence others.

Access and use of social care

Some of those we interviewed expressed the belief that there are very few older people in the Gypsy and Traveller community, reflecting the lower life expectancy of Gypsies and Travellers. “*In Gypsy culture they don't live to be old. Years ago, people would live to be old, but in these days, there's hardly any older people. During their late 50s, by that they're dead. If they live to be 60, that's a good age.*”

One woman who had had several operations explained that her mother, who lived in Ireland, came to help for months afterwards, and did the same when her children were born: “*We look to our own.*” When asked whether she would have wanted social services help after her operations, she said “*Someone coming in? No, not someone I didn't know.*”

However, it was clear from other interviews that the picture is more complex; it is not simply the case that Gypsies and Travellers have little demand for social care support because there are few older people in the community, and they prefer to seek help from family and friends, rather than statutory agencies.

One woman told us about her grandfather, who uses a wheelchair following a stroke, lives with the interviewee's parents, and had a lift installed near the caravan to enable him to get in and out of it. Interestingly, both her mother and father helped with caring for him. “*They did special care, to wash granddad and stuff, then my mum and dad did it. I think it was*

through social services, the hospital did it. It was helpful because it was a lot of hard work. This was after a stroke and he couldn't walk. It was 10 years ago and he's still there now."

Another interviewee told us she had previously cared for her grandmother who had lived in the caravan with her, but eventually, the grandmother had had to move to sheltered accommodation some distance away. The adult grand-daughter had initially tried to get help in the form of somewhere nearby that her grandmother could live "even if it was in housing", so that they could continue to see and help care for her. However, this had been refused, and they had been told to take the grandmother back to where she came from, resulting in the move to sheltered housing. The grand-daughter now has to travel to see her grandmother and cannot play such an active part in caring for her.

A woman in her 60s with mobility problems and poor literacy, living on a permanent site, told us that she needed an adaptation to help her use her front door: *"I just want a step, at my front door, so I can walk up and hold the handle. I just want a small step. Because if anything happens here, I can't have time to get out of the trailer, 'cos I shall fall over, won't I?"*

She had been unaware that she could get support from social services, until being told this by an outreach worker from FFT. Rather than seeking help from social services, she had contacted the man from whom she rented her trailer, who runs a business renting trailers to many Gypsies and Travellers across the South East: *"He's a bloke who rents these caravans out. We don't do it [the adaptations] he's the bloke that does it. He made that [step], but it's getting a bit wonky now. In two or three weeks he's coming out."*

She told us that, if people needed things like steps or a handrail fitted, they would often contact this man, and he would come and make it. She liked the fact that she had a personal relationship with him, and could specify what she wanted, and he did not charge extra for these things. However, it was clear from viewing his handiwork that he had no particular expertise in such adaptations, but rather would 'knock things up' on request. Thus, through using him rather than approaching social services, Gypsies and Travellers are running the risks of poor quality workmanship, and having adaptations that are not linked to wider health and risk assessments, nor do they meet health and safety standards. Furthermore, through this approach they are not benefiting from the expertise of professionals such as occupational therapists, physiotherapists, and reablement support workers, who could advise about other kinds of support, services and equipment.

With help from FFT, the same woman had received support from occupational therapists, providing equipment in her bathroom. It was apparent from this and other interviews that, even when people had received support from statutory services, they were not always sure who the help was from, and some were confused about the names and roles of various agencies. This is likely to be compounded by low literacy levels in the community, as people are not able to check or clarify such information by reading leaflets or posters. In this context, intermediaries and advice organisations play an important role in informing people and helping them to access social care support.

The mother of children with cystic fibrosis told us that she would like more aids and adaptations to help her children, but could not have these because her caravan was not big enough.

Stakeholders told us that the terminology of 'social care' was confusing to many Gypsies and Travellers, with people sometimes finding it difficult to understand the differences between 'social care', 'social services' and 'social workers.' They told us that people might be wary of

being asked about their experiences of 'social care' as they might interpret this to be about child welfare and safeguarding issues. There can be reluctance to approach social services or social care for help – even amongst older people - because of a widespread fear that they would take the family's children away. Instead, the Gypsies' and Travellers' culture of stoicism and self-reliance meant that people tended to 'make do' and 'not complain', and sometimes to improvise if aids and adaptations were needed.

It is important that health and social services recognise that families do play a very important role in Gypsy and Traveller communities in providing support to people who are ill, disabled or frail. However, it is not the case that Gypsies and Travellers never want social services support. There is a need for Gypsies and Travellers to have access to clear and easy-to-understand information about social care, and the different kinds of support available, and ongoing support in accessing such support. A project run by FFT in East Sussex, funded by East Sussex County Council, aimed to increase knowledge and uptake of adult social care within the Gypsy and Traveller community, employing a dedicated specialist outreach worker who was herself a member of the community. At the start of the project, there were no known Gypsies and Travellers accessing adult social care in the county, but as a result of the project 180 people received assessments and 80 received some form of adult social care support.

The national introduction of Personal Budgets would seem to offer great potential to the Gypsy and Traveller community. It is a government requirement that, by October 2010, local authorities should offer the option of a Personal Budget to all new people becoming eligible for social care. Under this initiative, people eligible for social care can choose to take the money as a cash payment and buy the support directly (in line with a support plan previously agreed with the local authority), rather than have the council manage and arrange the services for them. This gives people much greater choice and flexibility in how they use the money, for example in choosing and employing someone they know to come to their home to assist them, rather than receiving home care from a stranger, arranged through an agency. However, other research by OPM has found that Personal Budgets have been taken up most successfully by people who are confident, articulate, have strong IT and administration skills, and a wide network of family and friends to help them both manage the budgets, and think creatively about how the money could be spent⁷¹. It cannot be assumed that the introduction of Personal Budgets *per se* will benefit Gypsies and Travellers; targeted resources will need to be devoted to ensuring that Gypsies and Travellers are made aware of Personal Budgets and their potential, and given information, advice and support to enable them to access and utilise these effectively. This may be best achieved through the use of intermediaries such as voluntary sector organisations that already work with Gypsies and Travellers.

Cultural awareness

An overarching theme that emerged from many interviews with Gypsies and Travellers and stakeholders was the need for better cultural awareness amongst professionals.

"You get ones that are really nice and friendly, and understand that our lives are a bit awkward. But you get ones that think you're stupid, and a pikey, and you live in a caravan,

⁷¹ *Delivering personal budgets for adult social care: reflections from Essex*, OPM, July 2010

and that you're dirt. It's the individuals, their own prejudices. The hospital will treat me or you the same, they won't care that we're Travellers: the writing and the guidelines, they don't have different ones for us. It's the actual people that work there that give you the problem."

"If you had ones that understood that we are Travellers, that we can't help it if we can't make the appointments, because we're getting moved. For the health service, dentists, doctors, to have more understanding that it's not our fault. Obviously if we're coming to the doctor or dentist, it's because we're in pain or we need to see them. So if we miss that appointment, that's not our fault. It's because obviously we're getting moved."

The Primary Care Service Framework: Gypsy and Traveller communities⁷² says that all doctors and practice-based staff should receive mandatory cultural awareness training in relation to Gypsies and Travellers. It says this training should be planned and delivered by Gypsies and Travellers, working with, and supported by, professional staff.

The Pacesetters Programme, Gypsy, Roma and Traveller Core Strand piloted a number of projects designed to increase awareness of the culture and health needs of Gypsies and Travellers. These included:

- East Midlands SHA – three trusts worked together to train 30 members of the Gypsy and Traveller community as health ambassadors, to raise awareness of culture and health needs, break down barriers, and encourage trust and dialogue with healthcare staff.
- South West SHA – NHS Bristol developed staff awareness training on the culture and health needs of Gypsies and Travellers, resulting in a two-stage project with five members of the Gypsy and Traveller community recruited by a peer community development worker to a 'confident to present' training course, and staff training sessions being planned at the time of the evaluation report.
- Yorkshire and Humber SHA – an Introduction to Community Development and Health course was commissioned for members of the Gypsy and Traveller community. A core group of 4 – 5 people attended the first term, but interest was not sustained; lessons were learnt about the timescale for developing the project and approaches to developing capacity in a divided community. A neighbouring Gypsy and Traveller association was commissioned to deliver staff awareness sessions and ran three sessions attended by 55 staff.

The Pacesetters evaluation report⁷³ found that "overwhelmingly ... it was the opportunity to meet with [Gypsy and Traveller] community members and to have question and answer sessions with them that was considered by participants to be the most useful aspect of training." The report says that this "illustrated the extent of identified need for knowledge of these communities and the lack of awareness of their culture and their specific health needs that exists among staff." The evaluation repeatedly stresses the importance of Gypsy and Traveller involvement in both planning and delivering the training, and says this "cannot be overestimated."

⁷² *Primary care service framework: Gypsy & Traveller communities*, NHS Primary Care Contracting, May 2009

⁷³ *Pacesetters Programme Gypsy, Roma and Traveller core strand*, evaluation report for the Department of Health, University of Sheffield, April 2010

The report discusses the need for training to have clear and specific intended outcomes, and the limitations of cultural awareness training. It suggests training delivered to workplace groups or teams rather than to individual staff may be more effective, as "unless individual staff have the remit or authority to influence the ethos in the workplace the training of individual staff members will have limited success." The report stresses the importance of *reciprocal communication* between Gypsies and Travellers and health staff: "we saw clearly in the evaluation of the health ambassadors training sessions the importance of two-way learning and the need for facilitation for community members to be given an opportunity and confidence to ask questions of health staff."

Following the training, participants were contacted (by postal questionnaire and/or telephone interview) to find out what they had done as a result, or how they had used the training. There was "some success in identifying positive changes in practice, mainly in respect of improved communication." With one exception, it was too early to evaluate the longer-term outcomes of the training in terms of impact on Gypsies' and Travellers' experiences of health services. However, that exception appeared to demonstrate a positive impact: a focus group of Gypsy and Traveller health ambassadors who all attended one practice where the staff had received cultural awareness training reported a change in attitudes and behaviour, and "it was also notable that they identified the reciprocal nature of these changes through effective breaking down of defences."

The evaluation report concludes that "there are many lessons learned from the Pacesetter delivery of staff cultural awareness training, but of all of these perhaps the most important is that much time and planning with [Gypsy and Traveller] community members must be allowed for determining the aims and objectives, appropriate delivery and effective evaluation of outcomes."

Other primary care trusts have worked in partnership with local Gypsy and Traveller communities to develop resources to increase public and professionals' understanding of Gypsies' and Travellers' health and health needs. For example, Ormiston Travellers have worked with Cambridgeshire PCT to produce a Gypsy and Traveller Healthcare Information Guide for health professionals. As part of the Pacesetters project, NHS Bristol worked with community members and a range of agencies to produce a directory of resources for Gypsies and Travellers.

Conclusions and recommendations

There are many challenges for those involved in commissioning and providing services to meet the needs of Gypsies and Travellers. Gypsies and Travellers experience significantly poorer health outcomes than the settled population, and than other ethnic minority and socially deprived groups. The reasons are deep-rooted and complex, and many of the factors affecting the health of Gypsies and Travellers are inter-related. Gypsies' and Travellers' accommodation and travelling status have a major impact on their health, although the actual status and impact can differ, depending on individual circumstance. In order to fully understand Gypsies' and Travellers' health needs, it is also necessary to understand their distinct culture and cultural rules and expectations, the low levels of literacy and educational attainment amongst Gypsies and Travellers, and the multiple forms of deprivation and discrimination that Gypsies and Travellers continue to experience.

Despite the challenges involved, there are many local examples of good practice where public services have worked closely with Gypsy and Traveller communities to commission, develop and support services to meet their needs - it can be done. Although in many ways a hard-to-reach group, Gypsies and Travellers place great weight on trusted personal relationships. Investing in developing such relationships has often been a key to opening up communication between professionals and the Gypsy and Traveller community, leading to greater mutual understanding and respect, more culturally sensitive and appropriate services, and increased access and uptake. The most effective approaches have been ones that integrally involve Gypsies and Travellers, so that services are developed and co-produced with them, rather than imposed.

Within West Sussex, the views and experiences of Gypsies and Travellers interviewed for this report reflect national findings. Gypsies and Travellers in West Sussex experience the same issues of social deprivation, poor quality accommodation, uncertainty about being moved on, low health literacy, difficulty accessing health and social care services, and late presentation and low uptake of services as the rest of the Gypsy and Traveller population. They are also positive about some services, and some individual professionals and practitioners. The wellbeing of their children is a major motivating factor for Gypsies and Travellers, and influences many decisions about health, accessing services, and living, accommodation and travelling arrangements.

Finally, we recognise that this report is written at a time of major change for both health and local government organisations. The report is written for NHS West Sussex and West Sussex County Council. However, we hope that many others - and in particular the Director of Public Health for West Sussex and West Sussex GPs, as future commissioners of services to meet the needs of Gypsies and Travellers – will give this report their serious consideration and take action in response to the recommendations. Where future changes and responsibilities are already known, we have taken account of them in the recommendations.

Recommendations

Partnership working and an integrated approach

This report is being written at a time of major transition for everyone involved in health and public health. It is not currently clear exactly where and how health inequalities will be addressed within the reformed NHS; however, the role of Director of Public Health will continue to be essential to local partnership co-ordination, service integration and planning. As a first step, we recommend that the Director of Public Health shares the findings of this report on the health and social care needs of Gypsies and Travellers in West Sussex with key partners, and that an initial set of priorities is agreed between agencies. NHS West Sussex and West Sussex County Council should work in partnership with the district and borough councils, police, and other public services and relevant voluntary sector organisations to develop an integrated approach to working with Gypsies and Travellers, and to meeting the many needs of the Gypsy and Traveller community, recognising that these needs are often multi-factorial and inter-related. NHS West Sussex and West Sussex County Council should take a leadership role, to ensure such work is well understood, supported, communicated and adequately resourced to achieve ongoing momentum and clear, measurable progress. In the current financial climate it is unlikely that new resources will be available, and it is therefore essential that partners work together to explore how to use their resources most effectively, including joint approaches to commissioning and combining resources.

Work in partnership with East Sussex and Brighton and Hove PCTs, where appropriate

NHS West Sussex should also consider working in partnership with East Sussex and Brighton and Hove primary care trusts, to jointly commission services for / targeted at Gypsy and Traveller communities, where appropriate. Many Gypsies and Travellers travel across county boundaries, and use services in more than one PCT / local authority area. Working in partnership with East Sussex and Brighton and Hove PCTs should lead to greater service consistency, and more cost effective use of resources. The Director of Public Health can play a key role in driving and fostering such cross-boundary approaches.

Ethnic monitoring

NHS West Sussex and West Sussex County Council should work together with the district and borough councils, the police, housing associations, hospitals, schools, and other providers of public services to develop a consistent approach to ethnic monitoring of Gypsies and Travellers for public services across West Sussex, which is also consistent with the 2011 census. This should be taken forward as a matter of priority.

Improving cultural awareness

NHS West Sussex and West Sussex County Council should work together with organisations involved in support and advocacy for Gypsies and Travellers, members of the Gypsy and Traveller community, the district and borough councils and other providers of statutory and public services to develop a training programme designed to raise awareness of Gypsy and Traveller culture, health needs, and wider social needs. In line with the findings of the Pacesetter pilots, Gypsies and Travellers should be integrally involved in the planning,

design and delivery of such training, and the training should aim to develop a two-way dialogue and foster increased understanding between professionals and Gypsies and Travellers. The training should be delivered to a wide range of organisations and professional groups, including (but not restricted to) managers, clinical staff, GPs, and staff with customer-facing roles such as receptionists. Where possible, training should be delivered to staff in a whole group / whole team / whole practice. Uptake should be monitored and reviewed.

NHS West Sussex and West Sussex County Council should also consider commissioning and developing appropriate resources to increase awareness amongst Gypsies and Travellers of the services available to them, and to increase awareness amongst professionals of Gypsies' and Travellers' culture and needs. Gypsies and Travellers themselves should be integrally involved in the decisions about appropriate resources, and in their development. In developing resources for Gypsies and Travellers, commissioners and producers of such resources should be sensitive to the low levels of literacy and educational attainment within the community, and should ensure resources are fit-for-purpose and achieve their communication aims, for example through using formats such as easy-read written materials, video clips, DVDs, and through innovative and imaginative approaches.

Specialist and generalist services

NHS West Sussex, West Sussex County Council and other partners, should acknowledge the complex, multi-factorial and inter-related nature of the health and wider social needs of Gypsies and Travellers, the cultural context in which they are embedded, and the profound disparities in health outcomes between Gypsies and Travellers and the mainstream community.

NHS West Sussex, West Sussex County Council and other partners should work to ensure that generalist/universal services (aimed at and available to the general public, such as GP practices, maternity services, health visiting, dental practices, general hospital services etc.) are addressing the needs of Gypsies and Travellers, but should also recognise the importance of commissioning some specialist, targeted services for Gypsies and Travellers, which are able to devote dedicated resource and focus, develop long-term relationships with the Gypsy and Traveller community, bring deep insight and understanding of Gypsies' and Travellers' culture and needs, and share learning and expertise with other services.

Focus on child and maternal health

NHS West Sussex and West Sussex County Council should recognise the importance of child health as a public health priority (as identified by the Marmot report), and the very poor health outcomes experienced by Gypsies and Travellers in terms of child and maternal health, and should devote particular focus, emphasis and resource to addressing and improving maternal and child health within the Gypsy and Traveller community. This should involve working with GPs, midwives, health visitors, children's services and schools to ensure that they increase their understanding of the culture and health needs of Gypsies and Travellers, and take active steps to improve accessibility and provide culturally-sensitive services to Gypsies and Travellers.

Invest in developing relationships of trust between Gypsies and Travellers and professionals

NHS West Sussex and West Sussex County Council should recognise the huge importance placed by Gypsies and Travellers on trusted relationships with public service professionals, and the necessity of such relationships for effective service delivery to the Gypsy and Traveller community. This recognition should be reflected in their approach to commissioning, including acknowledgement that such relationships cannot be established at short-notice but require investment of time and resource over the longer-term, and also require a commitment to learn about, understand and respond to the specific culture and experiences of Gypsies and Travellers, to deliver culturally sensitive and appropriate services that meet Gypsies' and Travellers' needs.

When taking decommissioning decisions, commissioners should be mindful of the potential adverse impact on such relationships of trust, and the time and challenges involved for newly commissioned providers in building fresh relationships, especially if Gypsies' and Travellers' trust has been undermined by the 'withdrawal' of formerly trusted contacts from the decommissioned services. This is not to say that services should never be decommissioned, but rather than commissioners should be fully aware, and take full account of, the impact when making decisions about whether to recommission / decommission.

NHS West Sussex should seek to identify GPs within the county who express an interest in working with the Gypsy and Traveller community, and support them to become 'champions' for Gypsy and Traveller health, developing their own surgeries into models of good practice (based on the *Primary Care Service Framework: Gypsy and Traveller communities*, and working in close conjunction with local Gypsies and Travellers). Such GPs would be expected to share their learning widely with health professionals and others. NHS West Sussex should consider commissioning or providing additional funding to support such developments, which are likely to prove cost-effective in the medium to longer term (through earlier presentation and intervention, reduced use of urgent care services, etc.).

Outreach services

NHS West Sussex and West Sussex County Council should recognise the need to actively reach out to the Gypsy and Traveller community, and should commission outreach services targeted around the family, focusing on maternal and child health, and delivered by staff who have deep understanding and insight into Gypsy and Traveller culture and health needs, and appropriate training. Such services should link and work in partnership with other mobile children's services (e.g. playbuses) and children and family centres. Health education and health promotion should be a key part of the role of such commissioned services, including oral health.

Clarify abilities and responsibilities of health visitors

NHS West Sussex should make clear to the commissioned providers of health visiting services that they do have the discretion and flexibility, within current commissioning arrangements, to allow greater than standard frequency and intensity of contact with Gypsy and Traveller families, where this can be justified by the health visitor following an assessment of need and risk, and in line with a personalised care and support plan.

Should the responsibility for commissioning health visiting be placed with GP consortia under the ongoing health reforms, then GPs will need to work closely with the Director of Public

Health to ensure that future health visiting services are meeting the needs of Gypsies and Travellers.

Provision and quality of authorised sites for Gypsies and Travellers

NHS West Sussex and West Sussex County Council should explicitly recognise the clear links between adequate site provision and the health of Gypsies and Travellers, and should work in partnership with the borough and district councils to ensure that there are enough authorised sites and pitches, with good quality facilities, provided within West Sussex for Gypsies and Travellers. NHS West Sussex and West Sussex County Council should not let recent national policy changes lead to an impasse in the drive to develop and improve site standards in relation to health, for example regarding safety, access to clean water, showers, toilet facilities, lighting, pathways, vermin and pest control, and play areas. There should be further, ongoing investment in raising the standards of facilities at existing authorised sites. Given the history of tensions between settled communities and Gypsy and Traveller communities, there may be some local public resistance to investing resource in site improvement and development, especially at a time of constrained public funding. NHS West Sussex and West Sussex County Council should take a leadership role in explaining and communicating to the local settled community the importance and value of adequate authorised site provision.

West Sussex County Council should consider developing an appropriately situated and adequately resourced transit site in West Sussex, in discussion with the Gypsy and Traveller community, organisations supporting and working with Gypsies and Travellers, the police and other interested parties.

Address needs of Gypsies and Travellers in settled housing

NHS West Sussex should work in partnership with NHS trusts, primary care providers, housing authorities, and relevant voluntary sector organisations involved in health, welfare, advocacy and support for Gypsies and Travellers to address the needs of Gypsies and Travellers in settled housing, with particular focus on emotional and mental health needs. This should include, for example, commissioning mental health outreach and support targeted at the Gypsy and Traveller community, and delivered by staff who have deep understanding and insight into Gypsy and Traveller culture and health needs, and appropriate training. NHS West Sussex and West Sussex County Council should work with the district and borough councils and housing associations to ensure that staff in local authority housing services and in housing associations receive cultural awareness training and understand the cultural, health, housing and other needs of Gypsies and Travellers.

Guidance to GP practices about identification requirements for Gypsies and Travellers

NHS West Sussex should issue guidance to all GP practices in the county, making clear that that they do not need to insist on three forms of identification in order to see Gypsies and Travellers, reminding them of the particular difficulties that Gypsies and Travellers face in accessing primary care, and making clear that GP practices should apply discretion and flexibility when approached by Gypsies and Travellers, and should accept a wide range of forms of identification.

Dental and oral health

NHS West Sussex should review dental and oral health commissioning arrangements, to ensure oral health promotion is commissioned. NHS West Sussex should work in partnership with voluntary sector organisations involved in Gypsy and Traveller health, and with Gypsies and Travellers themselves, to identify specific dental practices with a particular interest in developing and promoting their services to Gypsies and Travellers, and to promote these to the Gypsy and Traveller community.

Consider introduction of patient-held records for Gypsies and Travellers

NHS West Sussex (and relevant successor bodies) should monitor the outcomes in Scotland and parts of England of the introduction of patient-held records for Gypsies and Travellers, and give further consideration to introducing such records, once more evaluative information is available, and in discussion with the Gypsy and Traveller community.

Invest in developing community capacity and social capital within Gypsy and Traveller community

NHS West Sussex and West Sussex County Council should aim to develop community capacity and social capital within the Gypsy and Traveller community, including through commissioning peer educator and/or peer advocate and/or health trainer roles as part of community service development to meet the needs of Gypsy and Traveller community.

Continuity of care and access to secondary care

NHS West Sussex and all health care providers should acknowledge that there is currently a lack of continuity of care for Gypsies and Travellers who travel, and that Gypsies and Travellers often have significant difficulty in accessing secondary care services, especially in keeping appointments if they are travelling, either due to enforced movement on or because they cannot return to an area for an appointment if there is no transit site and nowhere to stay. Whilst there are no straightforward solutions to this problem, it should, at very least, be included in the cultural awareness training, so that professionals have a deeper understanding of the factors that may lead to Gypsies and Travellers failing to keep appointments, and do not merely 'blame the individual'.

West Sussex County Council and other local authorities should explicitly recognise that a lack of adequate site capacity, including lack of transit site provision, has a direct impact on the quality and continuity of health and social care for Gypsy and Traveller community.

Supporting improved access to social care

NHS West Sussex and West Sussex County Council should work in partnership to commission and develop social care support for Gypsies and Travellers, recognising the current low levels of uptake – including of statutory entitlements - and the high degree of ignorance about, and mistrust of, social care and social services generally. NHS West Sussex and West Sussex County Council should recognise the important role of trusted intermediary organisations and commission them to provide information, advocacy, and support to enable Gypsies and Travellers to access Personal Budgets, aids and adaptations, and other forms of social care.

Appendix 1: documents reviewed

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Pauline Lane, Rachel Tribe, '*Towards an understanding of the cultural health needs of older gypsies*', *Working with Older People*, 14(2), June 2010, pp.23-30

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Zoe Matthews, *The Health of Gypsies and Travellers in the UK*, Better Health briefing paper 12, Race Equality Foundation, November 2008

Glenys Parry, Patrice Van Cleemput, Jean Peters, Julia Moore, Stephen Walters, Kate Thomas, Cindy Cooper, *The Health Status of Gypsies and Travellers in England*, report for Department of Health, University of Sheffield, October 2004

Glenys Parry, Patrice Van Cleemput, Jean Peters, Stephen Walters, Kate Thomas, Cindy Cooper, '*Health status of Gypsies and Travellers in England*', *Journal of Epidemiology Community Health* (2007); 61:198-204

Jean Peters, Glenys Parry, '*Health and use of health services: a comparison between gypsies and travellers and other ethnic groups*', *Ethnicity & Health*, Volume 14, Issue 4, August 2009, p. 359 – 377

Patrice Van Cleemput, Paul Bissell, Janet Harris, *Pacesetters Programme Gypsy, Roma and Traveller core strand Evaluation Report for the Department of Health*, University of Sheffield, April 2010

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Gypsies and Travellers: camp sites and trespass, House of Commons Library briefing, SN/SC/1127, August 2010

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Gypsies and Travellers: unauthorised development, House of Commons Library briefing, SN/SC/3248, July 2010

Gypsy and Traveller Strategy for England and Wales, Commission for Racial Equality, 2004

NHS Primary Care Service Framework; Gypsy and Traveller Communities, Primary Care Contracting, May 2009

Progress report on Gypsy and Traveller policy, Department for Communities and Local Government, July 2009

Report of Gypsy and Traveller Mental Health Event, Haywards Heath, Friends, Families and Travellers, 25 June 2009

The Health and Site Needs of the Transient Gypsies and Travellers of Leeds May 2004 to September 2004, Marion, M. Horton Associates, 2005

Working with Gypsies & Travellers, A brief note for Health Practitioners, Friends, Families and Travellers, 2009.

Local / area specific documents and literature

Professor Valerie Hall, Marya Sadouni, Avril Fuller, *Gypsies' and Travellers' experience of using urgent care services within NHS Brighton and Hove boundaries*, Friends, Families and Travellers, University of Brighton, Brighton and Hove NHS, 2009

An Assessment of the Accommodation Needs of Gypsies and Travellers in the District of Chichester, Chichester District Council, June 2007

Black and Minority Ethnic groups in Surrey and Sussex, West Sussex NHS Public Health observatory, January 2010

Comprehensive needs assessment for BME groups (including Gypsies and Travellers) in East Sussex, East Sussex Downs and Weald and Hastings and Rother PCT and East Sussex County Council, 2010.

Customer Insight, Gypsy Roma Traveller Workshop, summary report, May 2010, West Sussex County Council Customer Insight team

Friends, Families and Travellers (FFT), powerpoint presentation for *West Sussex Workshop 2009*.

Gypsy and Traveller Strategy 2009-12, Mid-Sussex District Council

Sussex Traveller Action Group (STAG), powerpoint presentation for *West Sussex Workshop 2009*.

West Sussex Gypsy and Traveller Accommodation Needs Assessment, David Couttie Associates, 2007

Appendix 2: stakeholder interview topic guide

Introduction

Introduce self and OPM.

Thank interviewee for agreeing to speak to us.

Explain OPM commissioned by NHS West Sussex to carry out a health and social care needs assessment for Gypsies and Travellers in West Sussex.

Explain have done some desk research, now doing 10 phone interviews to understand the key issues better.

Will then be doing c. 10 face-to-face interviews and 3 focus groups with Gypsies and Travellers, working in partnership with Friends, Families and Travellers (FFT) to arrange

Will hold a seminar to discuss initial findings with key stakeholders

Will produce a final report for NHS West Sussex, this summer, with findings and recommendations for commissioners

This scoping interview – will take c 45 mins to an hour, and we will be taking notes – will share draft notes to check accurate reflection of what was said.

If your area of work or knowledge means you are only able to answer some of the questions, then that would still be very helpful and welcomed.

Confirm OK to proceed

Information about the interviewee

Name:	Organisation:
Job title:	Contact details:

Interviewee background and knowledge

What kinds of contact do you have with Gypsies and Travellers in West Sussex?

How long have you worked with Gypsy and Traveller communities?

Which parts of the community do you work with? (specific groups, specific geographical areas, etc.)

Factors impacting on health

What kinds of things do you think most affect the health of Gypsies and Travellers in West Sussex?

Have any of these got better, or got worse, in recent years?

Do you think that there are differences in terms of health needs and impact on health, between people on unauthorised sites (roadsiders), people on authorised sites, and people in settled housing? Why?

Can you tell us anything about patterns of movement of the Gypsy and Traveller communities in West Sussex? For example, do numbers tend to increase at certain times of the year, and why? In which areas / sites? Does this impact on health?

Are there any factors that you think particularly affect specific groups, such as:

- children
- teenagers and young people
- women – including pregnant women and mothers
- men
- older people (aged 65 and over)
- People with disabilities

Prompts: if not previously mentioned, ask about: effects of poverty and living on benefits; smoking; diet and nutrition; ability to take exercise including access, alcohol use; drug use; violence including domestic violence, access to health education and health promotion, and if there are any other factors the interviewee wishes to mention.

Are there any factors that you think particularly affect Gypsies and Travellers in West Sussex, more than in other parts of the country?

Access and uptake of health and care services

Which health and care services do you think Gypsies and Travellers have difficulties accessing in West Sussex, or tend to have low uptake of, and why?

Prompts - as appropriate, depending on role and knowledge of interviewee: GPs, NHS Direct, dentists, midwives, health visitors, children's services, immunisations, hospitals A&E, hospitals non-A&E, opticians, screening services, family planning and sexual health, physiotherapists, OTs, chiropodists, adult social care (e.g. home care), care homes, carers' support services, mental health services, services to support end-of-life care.

Do you know of any services that Gypsies and Travellers have found particularly accessible and easy to use, and why?

Views of services, gaps and poor and good practice

Do you know of any groups that are *led by* Gypsies and Travellers, to help their communities? What do they do, and what difference has it made?

Do you know about any services that have made a particular effort to work with Gypsies and Travellers? Can you tell us what they did, and what difference it made? These can be examples from West Sussex, or from other parts of the country.

Are there any other kinds of service that we have not mentioned, that you think we should consider as part of our research on the health and social care needs of Gypsies and Travellers?

What do you think are the biggest gaps in services for Gypsies and Travellers in West Sussex, in terms of their impact on health and social needs?

What are the key things that you think services could do, to become better at meeting the needs of Gypsies and Travellers?

What are the main changes you think would make most difference to improving the health and wellbeing of Gypsies and Travellers in West Sussex?

Other sources of information

Can you suggest any other contacts or sources of information that can help OPM build up a picture of the Gypsy and Traveller communities in West Sussex, and their health and social needs?

Is there anything else you would like to add?

Thank you

Appendix 3: list of stakeholders interviewed

Name	Job title	Organisation
Neal Barton	Housing Policy and Performance Officer	Mid Sussex District Council
Lisa Bruton	Mental Health and Wellbeing Community Development Worker	Friends, Families and Travellers (FFT)
Susan Burlumi	Mental Health Community Support Worker	NHS
Thelma Edwards	West Sussex Personal Dental Services Oral Health Promotion Co-ordinator	NHS West Sussex
Geoff Foster	Equality and Diversity Liaison Officer	Sussex Police
Fiona Lucas	Health Visitor	Steyning health centre
Liz Markus	Insight from Marginalised Communities, Customer Focus Appraisal Adviser	West Sussex County Council
Esther Quarm	Team leader, Travellers and enforcement team	West Sussex County Council
Hazel Squire	Associate Adviser, Equality and diversity	West Sussex County Council
Shaney Torp	Health Visitor	Pulborough surgery
Lisa Williams	Community Development Worker	Sussex Travellers Action Group (STAG)

Appendix 4: interviews with Gypsies and Travellers topic guide

Explain the project

What we'd like to talk to you about

How the session will work

- Confidentiality
- What will be done with findings
- Recording and transcribing
- Any questions?

Introduction and warm up

Can you tell me a bit about you? Your age?

Name - reiterate can use alternative name / stay anonymous if prefer

Family

How long have you lived where you live now?

Have you ever done something like this before?

Factors affecting health

What does being healthy mean to you?

To others in the community?

In your view, what are the main health issues and needs of the Gypsy and Traveller communities?

In your view, what things affect Gypsies' and Travellers' health the most?

In your view, have any of these changed in the last few years?

In your view, what would most improve the health of Gypsies and Travellers?

Prompt: any other factors?

Knowledge and information

How do you find out about keeping healthy, and what is good and bad for your health?

How do you find out about health services e.g. doctors, dentists, hospitals?

How do you find out about social care e.g. help for older or disabled people, like getting aids put into caravans / trailers, or home care for older people?

Own health experience

How is your health at the moment?

[We had intended to use the EQ-5D standard health questionnaire for individual interviewees, but not for participants in group discussions. However, as it became clear that most interviews would take place in small groups, we discontinued use of this questionnaire]

EQ-5D questions: I'd like to ask you 5 questions. For each there is a choice of 3 answers. Please choose the answer that best describes your health today.

Mobility – please tick one

- *I have no problems in walking around*
- *I have some problems in walking around*
- *I am confined to bed*

Self-care – please tick one

- *I have no problems with self care (washing or dressing myself)*
- *I have some problems washing or dressing myself*
- *I am unable to wash or dress myself*

Usual activities – please tick one

(e.g. work, study, housework, family or leisure activities)

- *I have no problem with performing my usual activities*
- *I have some problems with performing my usual activities*
- *I am unable to perform my usual activities*

Pain / discomfort– please tick one

- *I have no pain or discomfort*

- *I have moderate pain or discomfort*
- *I have extreme pain or discomfort*

Anxiety/depression– please tick one

- *I am not anxious or depressed*
- *I am moderately anxious or depressed*
- *I am extremely anxious or depressed*

Ask to complete the EQ-5D visual scale:

Explain it and ask interviewee to draw line on scale to show how good or bad their health state is today.

Have you had any health problems? Can you tell me about them?

What kind of help or advice have you tried to get, for your own health? Where from?

check if sought help from West Sussex services?

Does anyone in your family have health problems? You don't have to give names, we're just trying to build a good picture of the health issues that people have.

Can you tell me who, and what the problems are?

What kind of help or advice have you tried to get for them, or have they tried to get?

check if sought help from West Sussex services?

Accommodation and perceived impact on health and health needs

Where are you living in at the moment – what kind of accommodation are you in?

What effect do you think where you live has on your health, and your family's health?

Can you say how and why it affects health?

What about other places where you've lived before?

What effects have they had on your health and your family's health?

How and why?

Prompt, if not already raised, ask about:

- Differences re. bricks and mortar housing, council sites, private sites, unauthorised sites/roadside

- Location, condition, and facilities

Are any of these issues better or worse in West Sussex than in other areas?

What about your health when travelling / moving between sites / on the road – how is it affected?

How does your health affect your ability to travel?

How does your health affect your ability to work or perform roles in your community (e.g. as mother, carer)

Access and use of services

What health services are you aware of?

What about social care services e.g. help for people who are old or disabled, help with getting aids for people who need help in their caravan?

What health services have you used?

What social care services have you used? (explain as above if needed)

Do you think health services meet your needs and your family's needs?

Can you say why / why not?

Which have been the best, and which the worst, in your experience? How and why?

What could be done to make services better for you and your family?

Prompt/explore – why would these be better for you?

Do you know about GP services in this area (West Sussex)?

How do you decide which GP to use?

What makes it easy or difficult to register with a GP?

How have you found using GPs in this area (West Sussex) compared with other areas?

What are the best and the worst things about GPs in this area?

Do you know about dentists in this area (West Sussex)?

How do you decide which dentist to use?

What makes it easy or difficult to register with a dentist?

How have you found using dentists in this area (West Sussex) compared with other areas?

What are the best and the worst things about dentists in this area?

Have you ever used hospitals in this area (West Sussex)?

Can you tell me about the last time you used a hospital - how was the experience?

[prompt: why went to hospital, if not already raised]

How did it compare with using other hospitals in other areas?

What are the best things and the worst things about hospitals in this area?

Are there other health services that you or your family have used?

What was good and what was bad about them?

How could they have been better, for you and your family?

Prompt – if not already raised:

Experience of children's health services?

Good/bad?

What could they do better?

Prompt if not already raised:

Experience of ante-natal and post-natal care i.e. services for women who are expecting, and for new mums

Good/bad?

What could they do better?

Prompt if not already raised:

Services for older people in family e.g. parents, parent-in-law, anyone else aged 65+

Their experiences of using?

Good / bad?

What could they do better?

Prompt if not already raised:

What about services for people with anxiety, depression, bad nerves or other mental health problems?

Experience of using / seeing family use?

Good / bad?

What could they do better?

Men's health

What do you think are the particular health issues and needs of Gypsy and Traveller men?

What are the particular issues for Gypsy and Traveller men, in using health services?

What could health services could do, to be more accessible to Gypsy and Traveller men?

And finally

What would make you more likely to use a service?

What would put you off?

In your view, do you think you've experienced discrimination from any health or social care professional, because you are a Gypsy / Traveller?

Are there any health or social care services that don't exist here (West Sussex), that you would like to see brought in?

If you could make one change that would improve the health of Gypsies and Travellers in West Sussex, what would it be?

Thank you for your time and for taking part.

Appendix 5: stakeholder workshop attendees

Name	Job title	Organisation
Neal Barton	Housing Policy and Performance Officer	Mid Sussex District Council
Lisa Bruton	Mental Health and Wellbeing Community Development Worker	Friends, Families and Travellers (FFT)
Anna Camp	Community Development Manager	Horsham District Council
Thelma Edwards	West Sussex personal dental services oral health promotion co-ordinator	NHS West Sussex
Kathy Kirk	Site manager, Adversane, Walstead and Horsgate Gypsy and Traveller sites	West Sussex County Council
Fiona Lucas	Health Visitor	Steyning health centre
Ross Maconachie	Shared Intelligence Officer	West Sussex County Council
Juliet McCafferty	Manager	Sussex Travellers Action Group (STAG)
Esther Quarm	Team Leader, Travellers and enforcement team	West Sussex County Council
Elaine Thomas	Health Development Manager	Chichester District Council
Lisa Williams	Community Development Worker	Sussex Travellers Action Group (STAG)
Phil Smith	Gypsy and Traveller Liaison Officer	Sussex Police