Executive Summary

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 project was conducted between May and September 2010. The findings 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.

The Gypsy and Traveller population of West Sussex

There are, as a broad estimate, between 3,000 and 3,500 Gypsies and Travellers living in West Sussex in 2010. The figure includes people living on authorised local authority and private sites, on unauthorised sites and developments, and in settled / bricks and mortar housing. This represents about 0.4% of the West Sussex population and compares with estimates of around 2,300 people of Bangladeshi origin and 3,500 people of Chinese origin in West Sussex. It also compares with latest Government estimates of around 368,000 Gypsies and Travellers across the UK.

In January 2010 there were at least 257 school aged children from Gypsy and Irish Traveller families in West Sussex (around 0.28% of all children in West Sussex state schools). The actual number of children from Gypsy and Traveller families in West Sussex schools is probably higher, as some under-reporting is likely.

Gypsies and Travellers live right across West Sussex:

- at 11 well established local authority run sites with a total of 124 pitches
- at 82 pitches at private authorised sites - concentrated in Chichester, Horsham and Mid Sussex
- on unauthorised sites and developments - concentrated in Horsham, Arun, Chichester and Mid Sussex. In January 2010, 59 of the 82 unauthorised sites and developments were on land owned by Gypsies and Travellers
- around two-thirds of Gypsies and Travellers nationally, and in West Sussex, are thought to live in settled / bricks and mortar accommodation, but there are no official figures.

Many Gypsies and Travellers in West Sussex follow seasonal patterns of travelling, with May, June, July and August being the peak months for people to travel. It is not unusual for
Gypsies and Travellers to use public services in more than one local authority or primary care trust area.

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. Even people with a pitch on a permanent site, or living in a house, may wish to travel for at least some of the time. Some families with children may stay in one place during term time, but travel during 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. Gypsies and Travellers who are now living in settled housing do not cease to identify as Gypsies and Travellers, nor do they lose their distinct cultural beliefs and practices, simply because of their current accommodation situation.

**Distinct culture and beliefs**

Gypsies and Travellers have lived and worked in the UK for over 500 years. They have a distinct culture and set of beliefs, including identifiable beliefs and attitudes to health. There is a strong emphasis on self sufficiency, and against seeking help from outsiders. Many Gypsies and Travellers are mistrustful of ‘the authorities’ e.g. police, local councils, and other statutory bodies including health and social care services. 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.

Families are organised according to strict hierarchies and gender roles. Women are expected to look after the household and take responsibility for child-rearing, cooking and cleaning. Men are considered responsible for supporting the household financially. Men rarely get involved in ‘women's issues' including health matters. It is common for Gypsy and Traveller men to feel awkward and embarrassed talking about their own health problems, or those of family members.

The extended family is very important in Gypsy and Traveller culture. Meeting up with family is a major reason for people to travel. At times of illness or crisis, people expect support from other family members, and long distances will be travelled to provide this. Groups of relatives often attend hospital and medical appointments, and expect to be involved in care and sometimes decision-making about health issues.

There are also strong cultural beliefs and rules regarding cleanliness and pollution. Having a clean home is considered an imperative, and for women, keeping the home clean is an important social role. Beliefs about pollution can manifest in concerns about additives and unnatural foods, and also medications and possibly vaccinations and injections generally. Cleanliness, hygiene and keeping clean are strongly associated with good health.
A high proportion of Gypsies and Travellers have very poor levels of literacy, and Gypsy and Traveller children have been found to have the lowest educational attainment of any minority ethnic group in England.

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

Overview
Previous research has shown that Gypsies and Travellers have possibly the worst health outcomes of any ethnic group in the UK. They have significantly lower life expectancy than the general population, and higher rates of miscarriage, stillbirth and infant deaths. Gypsy and Traveller women are twenty times more likely than the rest of the population to have experienced the death of a child.

The largest study of Gypsy and Traveller health in England found that the most marked inequalities, compared to the general population and to other ethnic minorities, were for respiratory problems including asthma and bronchitis, chest pain and anxiety. Gypsies and Travellers are more likely to have a long-term condition, health problem or disability than the general population.

OPM's interviews with Gypsies and Travellers in Sussex confirmed this picture of chronic and multiple health problems as common within the community. The 21 people we interviewed told us about their own health problems, including: anxiety, depression, paranoia, possible bipolar disorder, diabetes, mobility problems and arthritis, asthma, angina, heart attacks, heart aneurism, kidney problems, brain tumours, migraines and headaches, chronic pain, cataracts, severely limited vision, missing teeth and poor dental health, blackouts and repeated miscarriages. Many had multiple health problems. Interviewees also told us about a wide range of illnesses and ill health experienced by their family members.

Mental health
Mental health was a major theme in our interviews. Several women told us about their mental health problems - some severe and many long-lasting. Our interviews appear to confirm research evidence that poor mental health is a widespread and chronic problem for many women in Gypsy and Traveller communities. Other research has identified a myriad of issues contributing to poor mental health amongst Gypsies and Travellers, including pressures associated with travelling, social isolation, the experience of racism and discrimination, domestic abuse, and frustration and the feeling of 'having no control' over one's life or living situation.

Impact of travelling and accommodation status on health
Travelling and accommodation status are seen by Gypsies and Travellers to be major factors impacting on health. Our interviews found both positive and negative aspects associated with each different kind of accommodation, in terms on their impact on people's health, wellbeing and access to services. 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.

People told us of the stresses and uncertainties associated with travelling and living on the roadside (i.e. at unauthorised encampments) and of being moved on by the authorities, and the effects on their mental health. They also spoke of the difficulties making and keeping medical appointments in such circumstances, when they might have no electricity, no easy phone access, and not know where they will be staying in a few days time.

Interviewees also told us of the impact of living in settled housing on their health. The interviews appear to confirm that living in settled housing can either trigger or exacerbate depression and anxiety, amongst Gypsies and Travellers. People spoke movingly of their experiences of stress, anxiety and depression, and some contrasted their feelings living in a house with the much greater sense of freedom they felt on a site or travelling. Research evidence shows that living in a house is associated with long term illness, poorer health status and anxiety for Gypsies and Travellers, although the direction of any causal relationship is unclear.

Those living on authorised sites told us about the lack of access to clean water, lack of proper sewerage, and poor washing and showering facilities, and persistent problems with rats. On one site, parents have to take their children to the local leisure centre to shower, a bus ride away. Many expressed concerns about safety on sites – for example due to poor lighting, fencing with lots of gaps, and being situated close to busy roads with no footpaths. They were especially worried about the safety of children. For people of all ages – including older people and those with children – the cold was a problem when living on sites. It is difficult and expensive for Gypsies and Travellers to heat their homes adequately in winter, due to dependence on (costly) calor gas, and the design of caravans (e.g. it is not possible to insulate them effectively).

**Maternal and child health**

Most women we interviewed were positive about their experiences of midwifery, maternity, health visiting and other children's health services. They had serious concerns, though, about the wider factors affecting their children's health such as the quality and safety of sites, impact of noise, lack of safe play areas and experiences of bullying. Interviewees were positive about mobile outreach services such as the playbus in Brighton, especially liking the fact that health visitors came to sites and talked to everyone, not just mothers. They wanted to see the same approach taken in West Sussex.

**Men’s health**

The interviews re-enforced the impression, gained from previous research, that Gypsy and Traveller men often don’t go to the doctor, or present very late, and prefer to self-medicate rather than seek medical advice. Men were described as ‘shy’ or ‘embarrassed’ but despite their reluctance to seek help for their own health, they will attend their children’s health appointments, and drive women and children to appointments.

**Sources of information and trusted relationships**

Word-of-mouth and established trusted relationships are centrally important in transmitting knowledge and information about good health, keeping healthy, and about health and social care services to Gypsies and Travellers. Gypsies and Travellers gain their knowledge of good health and how to keep healthy mainly from family members, specifically mothers.
Family, friends, GPs, and organisations with a specific remit to provide information and advice to Gypsies and Travellers are important sources of knowledge about specific health and care services. There is considerable variation in the degree of trust that Gypsies and Travellers have in the site managers at local authority sites.

**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. It was apparent that a personal relationship with the doctor is highly valued. However, even people reporting good relationships with their doctors identified the difficulties that Gypsies and Travellers have in accessing GP services when travelling as a major issue impacting on health. Interviewees described a rigid (and unnecessary) insistence by some GP practices on seeing three forms of identification, before they will see a Gypsy or Traveller, on either a permanent or temporary basis. Some practices only accept very specific and limited forms of identification that many Gypsies and Travellers lack, such as passports and utility bills. Another issue was GP receptionists acting as ‘gatekeepers’, and sometimes being rude, abrupt, culturally insensitive and seeming to block, rather than facilitate, access to a GP.

**Dental services**

Gypsies and Travellers who were registered with a dentist were happy with the service they received. However, some had been unable to find an NHS dentist to register with, others had to travel from West Sussex to Brighton to see a dentist. Late presentation was a theme that emerged from the interviews, and difficulty accessing emergency dental treatment. Although the research evidence is limited, it suggests Gypsies and Travellers are significantly disadvantaged in accessing dental care and oral health, due to the inability to obtain regular check-ups and ongoing treatment. Stakeholders told us of their experiences of seeing young Gypsy and Traveller children with very poor teeth, and said that there is often poor awareness and understanding within the community about how to maintain good dental health. The importance of commissioning for oral health promotion and prevention work was stressed.

**Hospitals and secondary care**

Some people reported positive experiences of using hospitals; those who had used specialist services or received long-term treatment appeared to have developed trusting relationships with hospital staff, and seemed the most positive. Hospital staff’s attitudes to visitors and cultural awareness – in particular their understanding of the importance of extended family – were important. As with non-Gypsies, just a few experiences at a particular hospital can leave a very strong impression – positive or negative. As 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.

A major issue for Gypsies and Travellers is the lack of continuity when waiting for a hospital appointment following GP referral. People who travel – either voluntarily or involuntarily (e.g. due to enforcement proceedings and being moved on) – whilst waiting for an appointment have to start again ‘at the bottom of the list’ in the new area. This can lead to long delays in getting treatment, anxiety and uncertainty, and sometimes people being ‘lost to the system’. People were particularly concerned about the impact when waiting for hospital appointments for their children. Although there are no easy solutions to this problem, at the very least it
should be included in cultural awareness training, so that professionals understand the unpredictability of many Gypsies’ and Travellers’ lives, and do not respond to missed appointments by merely blaming the individual.

Social care

Our interviews revealed a complex picture in terms of Gypsies’ and Travellers’ demand for, access to, and use of social care. The terminology of social care is confusing; people can find it hard to understand the differences between ‘social care’, ‘social services’ and ‘social workers’. There can be reluctance to approach social services for help – even amongst older people – because of a fear that they might take the family’s children away. Instead, the culture of stoicism and self-reliance means people tend to ‘make do’, ‘not complain’ and sometimes to improvise if aids and adaptations are needed.

Families play a very important role in supporting people who are ill, disabled or frail. However, it was apparent from the interviews that Gypsies and Travellers do sometimes want social services support – but may have great difficulty obtaining the support they need. 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 social care.

With the national introduction of Personal Budgets, people eligible for social care can choose to take a cash payment and buy support directly, rather than have the council manage and arrange services for them. This gives people greater choice and flexibility e.g. in employing someone they know to assist them, rather than receiving care from a stranger arranged through an agency. This would seem to offer great potential to the Gypsy and Traveller community. However, it cannot be assumed that Personal Budgets per se will benefit Gypsies and Travellers; targeted resources 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 use these effectively. This may be best achieved through intermediaries such as voluntary sector organisations that already work with Gypsies and Travellers.

Cultural awareness

An overarching theme was the need for better cultural awareness amongst professionals – health, social care, housing and others. Some people had experienced discrimination and lack of understanding of their culture or the impact of travelling and accommodation situation on their health. Others we spoke to said they had not experienced any discrimination from health services.

In other parts of the country, various cultural awareness training programmes have been developed. Evaluation has highlighted the importance of having Gypsies and Travellers involved in the planning, design and delivery of such programmes, and the value of opening up a two-way dialogue between health professionals and Gypsies and Travellers. Some primary care trusts have worked with Gypsies and Travellers to produce resources to increase their awareness of available services, and to increase health professionals’ awareness of Gypsies’ and Travellers’ culture and health needs.
Summary of recommendations

Partnership working and an integrated approach
This report should be shared with key partners across West Sussex, who should agree an initial set of priorities, and develop an integrated approach to meeting the many needs of Gypsies and Travellers, including working together to make most effective use of limited resources. NHS West Sussex and WSCC should take a leadership role, as should the Director of Public Health.

Work in partnership with East Sussex and Brighton and Hove PCTs, where appropriate
NHS West Sussex should work in partnership with East Sussex and Brighton and Hove PCTs, where appropriate to jointly commission services for Gypsies and Travellers.

Ethnic monitoring
NHS West Sussex and WSCC should work with other public services in the county to develop a consistent approach to ethnic monitoring of Gypsies and Travellers, consistent with the 2011 census. This should be a priority.

Improving cultural awareness
NHS West Sussex and WSCC should work with Gypsies and Travellers and other organisations and public services to develop a training programme for a wide range of staff and professionals, to raise awareness of Gypsy and Traveller culture and needs. Gypsies and Travellers should be integrally involved in planning, design and delivery.

NHS West Sussex and WSCC should consider commissioning and developing resources to increase Gypsies' and Travellers' awareness of services, and to increase professionals' awareness of Gypsies’ and Travellers’ culture and needs. Gypsies and Travellers should be integrally involved.

Specialist and generalist services
NHS West Sussex, WSCC and other partners should acknowledge the complex and interrelated nature of the health and social needs of Gypsies and Travellers, their cultural context, and the huge disparities in health outcomes between Gypsies and Travellers and the mainstream community.

NHS West Sussex, WSCC and other partners should work to ensure that generalist/universal services address the needs of Gypsies and Travellers, but should also commission some specialist, targeted services for Gypsies and Travellers, that can devote dedicated resource and focus, develop long-term relationships, bring deep insight and understanding, and share learning and expertise with others.

Focus on child and maternal health
NHS West Sussex and WSCC should devote particular emphasis and resource to improving maternal and child health in the Gypsy and Traveller community.
Invest in developing relationships of trust
NHS West Sussex and WSCC should invest in developing relationships of trust between Gypsies and Travellers and professionals. This should be reflected in their approach to commissioning, acknowledging that relationships cannot be established at short-notice but require longer-term investment of time and resource.

When taking decommissioning decisions, commissioners should be mindful of the potential adverse impact on relationships of trust, and the time and challenges involved for new providers in building fresh relationships. This is not to say that services should never be decommissioned, but rather that commissioners should be fully aware, and take full account of, the impact when making decisions whether to recommission / decommission.

NHS West Sussex should seek interested GPs and support them to become ‘champions’ for Gypsy and Traveller health, developing their surgeries into models of good practice, and sharing their learning widely. NHS West Sussex should consider commissioning or providing additional funding for such developments, which are likely to prove cost-effective.

Outreach services
NHS West Sussex and WSCC should commission outreach services targeted around the family to reach out to Gypsies and Travellers, focusing on maternal and child health, and delivered by staff with deep understanding and insight into Gypsy and Traveller culture and needs. These services should work in partnership with other mobile children’s services and children and family centres. Their role should include health education and promotion, including oral health.

Clarify abilities and responsibilities of health visitors
NHS West Sussex should clarify to health visiting providers that current commissioning arrangements do allow them to exercise discretion and have more frequent contact with Gypsy and Traveller families, where this is justified by an assessment of need and risk, and in line with a personalised care and support plan.

Provision and quality of authorised sites for Gypsies and Travellers
NHS West Sussex and WSCC should work with borough and district councils to ensure enough authorised sites and pitches, with good quality facilities, within West Sussex. They should not let recent national policy changes lead to an impasse in the drive to develop and improve site standards in relation to health. There should be ongoing investment in raising the standard of facilities at existing sites. NHS West Sussex and WSCC should take a leadership role in explaining to the local settled community the importance and value of adequate authorised site provision.

WSCC should consider developing a transit site in West Sussex, in discussion with the Gypsy and Traveller community, organisations 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 with health, housing and voluntary sector organisations to address the needs of Gypsies and Travellers in settled housing, with particular focus on emotional and mental health needs. Staff in local authority housing services and housing
associations should 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 telling GPs they do not need three forms of identification to see Gypsies and Travellers, reminding them of the difficulties 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 with voluntary sector organisations involved in Gypsy and Traveller health, and Gypsies and Travellers themselves, to identify dental practices with a particular interest in developing and promoting their services to Gypsies and Travellers, and 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 give further consideration to introducing patient-held records for Gypsies and Travellers, 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 WSCC should 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 development to meet the needs of the Gypsy and Traveller community.

**Continuity of care and access to secondary care**

NHS West Sussex and all health providers should acknowledge the lack of continuity of care for Gypsies and Travellers who travel, and that Gypsies and Travellers often have significant difficulty accessing secondary care, especially keeping appointments if they are travelling. There are no straightforward solutions to this problem, but it should, at least, be included in the cultural awareness training so that professionals have a deeper understanding of why Gypsies and Travellers may miss appointments, and do not merely ‘blame the individual’.

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

**Supporting improved access to social care**

NHS West Sussex and WSCC 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 high degree of ignorance and mistrust of social care.
and social services generally. NHS West Sussex and WSCC 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.

How OPM carried out the project

OPM gained evidence and information in a number of stages:

**Desk research:** looking at local, regional and national data about the health and social care needs of Gypsies and Travellers, as well as case studies and examples of good practice.

**Interviews with stakeholders:** 11 telephone interviews with people with direct experience and knowledge of working with Gypsies and Travellers in West Sussex. OPM also met staff from Friends, Families and Travellers (FFT), a national information, advice and advocacy organisation for Gypsies and Travellers, based in Sussex.

**Interviews with Gypsies and Travellers:** face-to-face interviews with 21 Gypsies and Travellers, some individually and some in small groups. Everyone we interviewed was either living in West Sussex, or had direct experience of using services in West Sussex. There was a mixture in terms of gender, age, ethnic identification, location, housing situation and travelling status.

**Stakeholder workshop:** we held a workshop to discuss initial findings, test these against stakeholders’ experiences, and explore difficulties and challenges in providing services that meet the health and social care needs of Gypsies and Travellers in West Sussex, and possible new approaches.

The full findings were presented in a written report to NHS West Sussex and WSCC in October 2010.

Further information

Copies of the report are available on the NHS West Sussex website www.westsussex.nhs.uk

Further information can be obtained from:

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