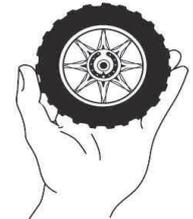


# Gypsies' and Travellers' experience of using urgent care services within NHS Brighton and Hove boundaries

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Friends, Families and Travellers



University of Brighton



Brighton and Hove

Professor Valerie Hall

Marya Sadouni

Avril Fuller



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## **Executive summary**

The study was carried out by the University of Brighton in collaboration with Friends, Families and Travellers and was funded by NHS Brighton and Hove (formerly Brighton and Hove City Teaching Primary Care Trust) as one of its 'Choosing Health' projects.

The study investigated the extent to which Accident and Emergency (A&E) or other urgent care services are being used by Gypsies and Travellers and examined whether more appropriate and effective interventions could be put in place to meet their urgent healthcare needs.

We took a participatory research approach using an exploratory case study design, which enabled us to identify the unique characteristics of the situation and the multiple perspectives of those operating within it. The participatory approach ensured that we included everyone who had an interest in the area and made sure that Gypsies and Travellers had a say in how the research was done and in agreeing the research findings.

We interviewed twenty five people from the Gypsy and Traveller community who had recently experienced a serious illness or injury. We interviewed people who were housed, who lived on authorised sites, or who were living by the roadside. We were unable to extract hospital data on the range of illnesses and injuries, or the number of adults and children presenting at the hospital, because their monitoring system does not collect data on this ethnic group.

We found that the large majority of participants used either primary or hospital-based urgent care services when experiencing serious illness or injury, but their experiences were often sub optimal. Gypsies and Travellers, similar to the general population, appear to have very clear and logical strategies for choosing to access particular urgent care services, which contradicts the perception that they use hospital services inappropriately. However, their experience of using the services is less favourable in terms of poor staff attitudes and perceived poor health outcomes when compared with data from the local general population and they do not currently use the complaints system.

Gypsies' and Travellers' health overall is poorer than others in socially deprived areas and they have poor health expectations. Therefore, in order to increase trust and enhance uptake, services need to be culturally sensitive and respond to their lifestyle needs.

A number of recommendations are made which would enhance services locally, such as:

- *Delivering culturally appropriate provision to staff in all front line health services.*
- *Improving communication between the health care providers and Gypsies and Travellers to engender confidence in agreed treatment options.*
- *Strengthening the role of the outreach worker to support the housed population to achieve better dialogue with GPs and other health professionals and enable ongoing review of treatment effectiveness.*
- *Strengthening the role of the outreach worker in terms of liaison between health professionals' awareness of Gypsies and Travellers living on local sites and their health care needs.*
- *Promoting a family and community approach to delivering services to Gypsies and Travellers which would provide an opportunity to work with the whole community on health promotional activities.*
- *Strengthening links with the Gypsy and Traveller community to explore ways of reducing the response time for serious injury and illness by offering First Aid and Cardio Pulmonary Resuscitation training, with the potential for providing first aid equipment to highly mobile groups.*
- *Increasing Gypsy and Traveller knowledge of local services by using creative ways of disseminating information*
- *Promoting awareness of the complaints system and seeking ways to provide an advocacy system*
- *Ensuring all groups are properly represented by holding separate consultations for Gypsies and Travellers and other marginalised groups and involving them in designing local services*

Many of these recommendations require mediation and reports point to the efficacy of employing specialist health outreach staff to work with Gypsies and Travellers rather than relying on health staff for ethnic minority groups and homeless people (Cemlyn 2009:58). This research highlights the important work that has already been done by Friends, Families and Travellers' outreach workers, who have the credibility within the community to advise people about services and support them in dealing with health issues. This research has also shown that the outreach role is effective, but could become even more proactive.

Urgent care services need to be seen within the context of the social determinants of health. Improvements in the health of Gypsies and Travellers involve the co-operation of a range of other agencies, including the local authority, education services and the police force. Practical initiatives, such as working with the local authority to signpost sites so that emergency services can reach Gypsies and Travellers more quickly and enabling patients requiring follow-up care to stay in the area, can lead to improved outcomes.

A number of national initiatives are also recommended, which include investigating innovative ways of maintaining GP continuity within the travelling lifestyle and fostering trust and understanding by encouraging the Gypsy and Traveller community to be involved in designing local and national services. As a longer term initiative thought should be given to encouraging members of the Gypsy and Traveller population to consider becoming members of the NHS workforce.

In conclusion, using a participatory approach, which fully involved Gypsies and Travellers in the research design and operation, has led to a greater understanding of the experiences of the community and opened up a dialogue between health and other services. It has resulted in normally suspicious Gypsy and Traveller families opening their doors to researchers and genuinely believing that change can come about as a result of their voices being heard.

## 1. Introduction

It is recognised that Gypsies' and Travellers' health overall is poorer than others in socially deprived areas (Parry et al, 2007). They have poor health expectations (Van Cleemput et al, 2007) and make limited use of health care provision (Triese and Shepherd, 2006). Van Cleemput et al (2007), reporting on health related beliefs in Gypsies and Travellers, found that the experience of poor health was normalised and accepted. The concept of self reliance and staying in control, together with fatalism and fear of death, characterised their health beliefs and these attitudes affected health-related behaviour. Their reluctance to acknowledge poor health and seek outside help is compounded by health professionals' lack of knowledge about this group (Goward et al 2006).

Little is known about Gypsy and Traveller uptake of urgent care services because despite being recognised as an ethnic minority group under the Race Relations Act of 1976 there is a lack of statistical monitoring data for this group. There have been perceptions that their travelling lifestyle results in a heavy reliance on A&E services. However lack of statistical monitoring contributes to their invisibility in terms of mainstream service use and makes it difficult to determine their health needs.

Nationally, each year A&E departments are seeing increasing numbers of patients: in Brighton and Hove this amounts to almost 100,000 a year. Urgent services, which includes A&E, are considered to be those required by people with serious, recent injuries and illnesses; although there is a perception that many people go to A&E departments as soon as they feel ill, or have an accident, and do not always consider the alternatives. However, it is recognised that these so-called inappropriate attendees have logical reasons for attending the A&E department, rather than attending GP surgeries (Walsh 1995). A wide range of reasons were reported, which included feeling that the treatment in A&E was better than that provided by their GP; not wishing to wait for an appointment; that they would have been referred to A&E by the GP anyway; or that they needed an X-ray, which the GP could not provide. Murphy (1998) also challenges the notion of inappropriate attendees and proposes that complex social and psychological factors also influence decisions to attend.

Many hospitals are now offering a range of services, such as Minor Injury Units and Walk-in Centres with 'urgent' and 'first line care' facilities, to reduce the perceived 'inappropriate' use of urgent services. Attendance at Walk-in Centres highlights the potential for lack of continuity of care from a regular GP if patients are accessing a GP at A&E (Lawrence 2007). This problem is compounded for Gypsies and

Travellers who are not registered with local GPs and are not able to stay in the area to take advantage of follow-up or after-care. There is a need to understand how Gypsies and Travellers use these services and whether the services they access are the most appropriate for their needs.

The area of this study was initially proposed by the Patient and Public Engagement Manager, NHS Brighton and Hove (formerly Brighton and Hove City Teaching Primary Care Trust). Friends, Families and Travellers (FFT)<sup>1</sup> and the University of Brighton were invited to develop a study to investigate the extent to which A&E, or other urgent care services, are being used by this minority group. In addition, the study planned to examine whether more appropriate and effective interventions could be put in place to meet Gypsies' and Travellers' urgent healthcare needs. The study was funded by NHS Brighton & Hove as one of its 'Choosing Health' projects.

FFT has been operating the Sussex Traveller Health Project since 2003. Its remit is to establish a model of Traveller participation in the promotion of health, to develop the skills of Traveller women in providing community-based health services, to assist in the dialogue between Travellers and health service professionals, as well as reducing inequalities in existing services and highlighting gaps. It was initially funded by the Department of Health, but more recently has received funding from NHS Brighton and Hove to employ a Specialist Traveller Health Adviser. The Sussex Traveller Health Project also has strong links with the Midwife for Substance Misuse, Homeless and Travellers at the Royal Sussex County Hospital, who has established good relationships with the local Gypsy and Traveller community and offers a specialised service to them.

## **2. What is urgent care and how is it organised in Brighton and Hove?**

The Department of Health (2006:12) defines the term 'urgent care' as "the range of responses that health and care services provide to people who require – or who perceive the need for – urgent advice, care, treatment or diagnosis. This includes transport and the emergency services provided by the Ambulance services. People using services and carers should expect 24/7 consistent and rigorous assessment of the urgency of their care and an appropriate and prompt response to that need"

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<sup>1</sup> Friends, Families & Travellers (FFT) was established in response to the 1994 Criminal Justice & Public Order Act and is one of a number of leading organisations seeking to address the problems facing the Traveller and Gypsy community.

The Steering Group adopted this as a working definition for the research.

Urgent care therefore falls between routine care and needs which are life threatening (ie. emergency) and is wider than merely 'A&E' services. It could comprise a wide range of responses to an urgent problem which could be, for example, self treatment at home, advice, community services or pharmacies.

This study was undertaken at a time when Accident and Emergency (A&E) provision within NHS Brighton and Hove boundaries was changing to provide more comprehensive urgent care services. Emergency care services are provided by the Brighton and Sussex University Hospitals NHS Trust (BSUH) A&E departments, situated at the Princess Royal Hospital (PRH) in Haywards Heath<sup>2</sup> and the Royal Sussex County Hospital (RSCH) in Brighton. The RSCH also offers a range of other urgent care services, including self or GP referral to rapid access clinics. Urgent care is also provided through GP surgeries within the NHS Brighton and Hove area. The PRH does not have a designated urgent care service, but patients can access a GP Out of Hours Service.

An element of urgent care can be provided by every GP and is another reason why NHS Brighton and Hove encourages people to register with a GP, as well as being able to build up a personal relationship and access the full range of services, such as screening, and maintain continuity of care. Patients should expect to get an appointment to see a health practitioner (such as a nurse) within 24 hours and an appointment to see a GP within 48 hours. If an 'urgent' appointment is requested, a patient should be seen that day.

Following changes in GPs contracts, GP practices are no longer obliged to provide their own 'Out of Hours' service. NHS Brighton and Hove is responsible for ensuring that Department of Health services are available and contracts with 'South East Health Limited' to provide this service. In Brighton and Hove the service is based at the Urgent Care Centre. A triage assessment nurse answers calls to this service and the patient's needs are met either by telephone advice, an appointment at the Urgent Care Centre, or a house call.

The Urgent Care Centre also sees people who have arrived at the A&E department as walk-in patients. At reception the patient registers and is assessed. Those with minor illnesses are generally seen by GPs and those with minor injuries are

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<sup>2</sup> Whilst the Princess Royal Hospital is in West Sussex, and therefore out of the Brighton and Hove boundaries, it was decided to include it in this study because it is part of the BSUH NHS Trust provision. Highly mobile families may access services at either hospital.

generally seen by Emergency Nurse Practitioners. Patients requiring diagnostics (blood tests or X-ray), or emergency care, may be directed to the Emergency Department, although from April 2009 GPs have access to diagnostics. Support exists for helping those people who have difficulty in getting an appointment or registering with a local GP.

The Urgent Care Centre and the Emergency Department together make up A&E services. Those coming into the Urgent Care Centre are either Out of Hours patients (have already had some form of assessment and have an appointment) or are walk-in patients.

These changes in services are being communicated to the public through information leaflets<sup>3</sup>. Establishing effective ways of letting people know about the new service is crucial to encouraging people to accept them and ensuring a good uptake.

### **3. What did we want to find out (specific objectives)?**

We wanted to find out about the current use of urgent care services by Gypsies and Travellers within the Brighton and Hove area.

More specifically we wanted to:

- 1. Describe the total range of recent serious symptoms/traumatic incidents reported by Gypsies and Travellers.*
- 2. Describe the recent serious symptoms/traumatic incidents of Gypsies and Travellers who used urgent care services.*
- 3. Describe what action/treatment/referral occurred for Gypsies and Travellers who used urgent care services.*
- 4. Describe what actions or treatment options were taken by Gypsies and Travellers who reported recent serious symptoms and traumatic incidents but did not use urgent care services.*
- 5. Determine the factors influencing Gypsies' and Travellers' decisions as to where to seek help and from whom.*
- 6. Compare the average number and pattern of individual Gypsy and Traveller child attendances against the average number for the total population in Brighton and Hove.*

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<sup>3</sup> See for example, Leaflet 'Right Care, Right Place, Right Time' produced by NHS Brighton and Hove.

The outcome of this study will be useful to policy makers, service commissioners and developers, as well as Gypsy and Traveller organisations and health outreach workers. There is currently no research identifying rates of 'urgent care' service usage for Gypsies and Travellers, other than in children, as reported by Beach (2006). The research will report on the number of Gypsies and Travellers accessing the 'urgent care' services, what symptoms and injuries they present with and why they chose to access this particular service. It will also reveal the actions taken for symptoms and injuries when 'urgent care' services were not accessed. This is important because the potential need for 'urgent care' services may be masked by the choice of other inappropriate options, such as self care or less specialist services, which may be inappropriate and result in sub-optimum care.

#### **4. How did we go about finding out?**

##### **Research design**

We used an exploratory case study approach, which focussed on Gypsies' and Travellers' usage of urgent care services within the boundaries of NHS Brighton and Hove over the period of a year.

NHS Research Ethics and Governance approval was not required, although the advice to notify NHS Brighton and Hove and the BSUH Clinical Effectiveness Departments was followed. The study was approved by the University of Brighton Research Ethics and Governance Committee.

We planned to use two main sources of information in this study:

1. NHS Trust statistical audit information monitoring Gypsy and Traveller attendance for 'urgent care'
2. Interviews with Gypsies and Travellers who reported symptoms or injuries that would normally require urgent treatment

Appendix 1 contains more detail on data sources mapped against outcomes.

The case study approach allowed for the collection of different types of information, such as statistical data and interview data in order to build up a full picture. It allowed researchers to concentrate on specific instances, or situations, and then attempt to identify the various interactive processes at work (Stake 1995). This

approach recognises the importance of the unique characteristics of individual situations and the multiple perceptions of those operating within them. We also took a participatory approach to the case study because we wanted everyone who had an interest in the area to be involved. More particularly, we wanted to make sure that the Gypsies and Travellers had a say in how the research was done and in agreeing the research findings (Hall 2009).

We analysed the interview data thematically, using the framework approach for applied policy research described by Ritchie and Spencer (2002). This involves a systematic process of sifting, charting and sorting material according to key issues and themes, based on a framework of the aims and objectives set for the study.

The framework approach was chosen because the research objectives were clearly set and output from the research needed to be appropriately targeted towards providing 'answers' in the form of greater illumination or understanding of the issues (Ritchie and Spencer 2002: 307). In our research we wanted to shed light on the urgent health care needs and experiences of Gypsies and Travellers, with the aim of improving their health outcomes.

The peer researchers and researchers analysed the data in a series of workshops and the final analysis was presented to the Steering Group for validation. We also presented clear records of our analysis methods and the techniques we used to ensure transparency of analysis, so that policy makers could feel confident in acting on our findings.

### **The role of the Steering Group**

The original research design was agreed collaboratively between the Patient and Public Engagement Manager, NHS Brighton and Hove, FFT and a researcher from the University of Brighton. The research design was presented to a Steering Group, which represented the parties who had an interest in this study. The Steering Group originally consisted of representatives from FFT, the 'Out Of Hours' service, NHS Brighton and Hove, BSUH Specialist Midwife for Substance Misuse, Homeless and Travellers; South East Coast Ambulance Service NHS Trust, and representatives from the local Gypsy and Traveller community. A General Practitioner from the services for the homeless expressed interest in joining the group but, unfortunately, was not able to attend. Despite a number of invitations we were unable to get a regular representative from the urgent care service at the hospital. The members of the Steering Group were consulted on the ongoing research operation, which meant it changed slightly over time. Feedback on early findings, when it was recognised

that other services had a part to play in health improvements, resulted in new representatives for the Brighton and Hove City Council and the Head of Equality, Diversity & Human Rights at BSUH joining the Steering Group.

The Steering Group was chaired by a Romany Gypsy from the local Gypsy community and two peer researchers recruited from the Gypsy and Traveller community became members of the Steering Group.

Although representatives from hospital urgent care services and GP services weren't able to attend regularly we believe that the make-up of the Steering Group, and particularly the involvement of Gypsies and Travellers, ensured that the research fully represented the multiple perspectives that contribute to the understanding of issues surrounding Gypsies and Travellers' use of urgent care services.

### **The role of the peer researchers**

The peer researchers helped design the interview schedule, recruited Gypsies and Travellers to the research, collected the interview data and were involved in the analysis, compilation of the report and dissemination of the findings.

The two peer researchers, Marya Sadouni and Corrina Adams, recruited via the Sussex Traveller Health project, came from Romany Gypsy and New Traveller backgrounds. Although the study was to concentrate on Gypsies and Irish Travellers, an understanding of the travelling lifestyle was the important issue and as researchers would conduct the interviews together it was not necessary for both researchers to have Gypsy or Irish Traveller backgrounds. Sadly, in the course of the study Corrina became seriously ill and, following a short period in hospital, died. Whilst the devastating and untimely death of this young New Traveller, who was mother to a young family, shocked the team, they agreed to continue with the research, as trying to improve poor health outcomes for Travellers was the very reason why it was being carried out. Fortunately, FFT was able to recruit Avril Fuller, who also has a Gypsy background, to join the research team.

As the peer researchers already worked with FFT they were known to many of the interviewees. This meant they were better accepted by the community, provoking less suspicion than non-Gypsies and Travellers. Their knowledge of the culture and day to day life enabled them to arrange interviews for times they knew would be most convenient and ask questions in a way that helped understanding and resulted in fuller answers. The disadvantage of peer researchers is that potential interviewees may be reluctant to disclose personal information to someone who knows them. This

did not appear to be a problem and the peer researchers received full training regarding confidentiality and data storage by colleagues in FFT who have many years' experience in supporting Gypsies and Travellers. University of Brighton researchers provided training for the peer researchers, who gained skills and confidence through participating in the research process. They played a full part in data analysis and interpretation workshops and also contributed to the content of the report.

They developed a sense of ownership of the research and felt that the process of interviewing allowed them to relate to community members in a different way. One peer researcher commented that she felt that Gypsy and Traveller families had opened their doors to her; they were interested in the results of the study and genuinely believed that change could come about as a result of their voices being heard. Both peer researchers felt the research had already started to make a difference and one felt she had become more proactive as an outreach worker. This led to a GP and nurse going onto one of the sites to offer immunisation against measles and, in a similar example, the Gypsy chair of the Steering Group enabled an invitation for midwives to visit an Eastbourne site.

## **5. Who was chosen to participate?**

The research concentrated on adults and children from the Gypsy and Traveller community accessing hospital services at the RSCH in Brighton, the PRH in Haywards Heath, or GP services. Gypsies and Travellers were recruited through contacts made with roadsiders (the preferred term for those actively travelling and staying on unauthorised sites), those using the local authority sites<sup>4</sup> at Horsdean, Fairbridge Way and Burgess Hill, and housed Gypsies and Travellers.

These locations were chosen with the aim of getting information about Gypsies' and Travellers' access to services within the NHS Brighton and Hove boundaries, but due to the nature of travelling, some respondents talked about their experiences of accessing urgent care while they were staying in other parts of the country.

The term 'Gypsy and Traveller' used here encompasses both Romany Gypsies and Irish Travellers, each with a separate ethnic identity, but sharing many aspects of a common cultural identity with traditional travellers. Our study excludes New

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<sup>4</sup> Horsdean is a transit site situated in Brighton and currently allows stays for 4 weeks at a time in the Summer, and up to 12 weeks in Winter.

Travellers and Occupational Travellers, who live in this way for a variety of reasons but are not of the same culture and under the terms of the Race Relations Act, are considered to be social groups (see Appendix 2 for details of this group.) However, the Steering Group felt it was important for New Travellers to become recognised as a group with specific needs, as they are currently not protected under legislation to the same extent as traditional travellers

## **6. How were they recruited?**

Gypsies and Travellers were invited to take part by peer researchers or FFT outreach workers, who went onto sites to talk about the study, and also by the FFT's local newsletter. Much recruitment was done through word of mouth, so that people who were not able to read were not excluded. Those who had agreed to be interviewed (participants) were also asked to pass on information and suggest names of others who might be interested in participating.

If Gypsies and Travellers expressed interest in participating they were given an information sheet (Appendix 3), or the information was read to them by peer researchers, or by other outreach workers. Every effort was made to ensure there was a sufficient amount of time between giving information and gaining consent. However, we soon realised that we had to reduce the time period between information giving and consent, as potential participants were moving on before the peer Reviewers returned to interview them. Consent was recorded in writing if possible (Appendix 4), but usually it was digitally recorded at the beginning of the interview. The information sheet contained telephone numbers of contacts at both the University of Brighton and FFT for further information. It also contained the name and telephone number of an independent person at the University of Brighton or FFT should they be unhappy about any aspect of the research process.

Participants were given a £5 supermarket voucher to thank them for their time and involvement.

## 7. How many people did we interview and what did we ask them?

We undertook twenty five interviews in total. We recruited Gypsies and Travellers who were housed, people who lived on authorised sites and roadsiders who were staying on unauthorised sites. Roadsiders were particularly well represented but unfortunately, due to the timing of the research, we missed a large number of potential participants who normally come to meet up with family members in the summer. However due to the travelling lifestyle and a reluctance to be interviewed, the number recruited was unlikely to be high and we had estimated that a number between a minimum of seven and a maximum of forty participants was likely. Therefore our final figure of twenty five was well within the anticipated range. Factors such as age and gender were important in view of dominant cultures in the Gypsy community. We were pleased that we were able to recruit a substantial number of men (see Table 2 for details) because anecdotally they are considered less likely to participate. The age profile ranged from babies and small children through to an elderly participant.

Number of people interviewed	Location
6	Housed
6	Official sites
13	Roadsiders
<b>25</b>	<b>Total</b>

Table 1

Interviewees by gender	
18	Female
7	Male

Table 2

Quite a few people were unwilling to take part and we thought it was important to find out why. From January 2009 onwards we kept records, which told us that nineteen people who had been invited to be interviewed had declined. They said they did not want their views reported, or they didn't like doing interviews. Others were going away on holiday, or leaving the area. One person clearly stated that they felt they might be discriminated against if they gave their views. In addition, ten people who originally agreed to be interviewed subsequently cancelled, often because of family emergencies, or moving away. To overcome these problems we changed our method of recruiting from March onwards, reducing the time between information giving and consent to interview, while still leaving sufficient time for proper decision-making.

Number of people who declined	Location
9	Housed
3	Official Sites
7	Roadsiders
<b>19</b>	<b>Total</b>

*Table 3*

We had originally intended to interview at three specific times in the year: summer, spring and winter, in order to capture seasonal changes. We wanted people to tell us about their experiences in the last three months, but they actually told us about events further back than this. Even though we were not able to match the experiences to the seasons, we felt we obtained information about a wide range of serious symptoms and injuries. We did pick up some reports of depression and anxiety disorders but no-one spoke about severe mental health problems, drug abuse, or attempted suicide. We did not hear any reports of cancer, or sexually transmitted infections, although – given the urgent care nature of our research – we might not have expected to get this information. Although the participants did tell us about maternity experiences, they were too far in the past to include. We did not ask about dental services, but one participant spontaneously commented on the lack of services.

People told us about their own experiences and those of others, including children. To ensure information presented is accurate, we have only included reports about people's own experiences and that of the children in their families.

### **What did we ask Gypsies and Travellers?**

We started off with a list of interview questions in order to find out about the outcomes listed in Section Three. The peer researchers and Steering Group Chair helped us to make the questions easy to ask and easy to answer, but after the first set of seven interviews we realised we needed to make some changes. We therefore changed the focus of the questions to ensure better coverage of all urgent services, including those offered by a GP. After discussing the analysis of the first seven interviews with the peer researchers, we added questions about taking other people's medication and knowledge of services. We also simplified the schedule to ensure better consistency of questions across interviews.

## 8. What did we find out?

Analysis took place at three points during the collection of the data. The researchers and peer researchers began the process of familiarisation, immersing themselves in the data to gain an overview of the body of information gathered.

As Ritchie and Spencer describe (2002:312) “although [the researchers] will have been involved in some, if not all, of the data collection, and will have formed hunches about key issues and emergent themes, it is important at this stage to set these firmly in context by taking stock and gaining a feel for the material as a whole.”

Our thematic framework was already defined by the specific objectives of the study and to this we added the additional issues raised by Gypsy and Traveller participants, categorized into analytical themes that we felt represented the data.

Therefore, what the Gypsies and Travellers told us is presented in two separate parts. The first answers the specific questions we set (see specific objectives above) and the second provides more detail and reports the important issues that arose from our interpretation of what people said (emergent issues).

### **Questions that we set out to answer (specific objectives)**

1. *Describe the total range of recent serious symptoms/traumatic incidents reported by Gypsies and Travellers.*
2. *Describe the recent serious symptoms/traumatic incidents of Gypsies and Travellers who use urgent care services.*

Participants talked about a range of episodes, some of which were not recent and for some of which they did not use local services. We have tried to identify, where possible, people’s *recent* experience of *local* services and only include those. Other data regarding past experience has been used as background information. We have not divided the experiences between primary and urgent care providers, because in many cases Gypsies and Travellers accessed, or were asked to access, both during one episode.

We were unable to extract information about the overall number of adults attending hospital-based services as originally planned, because hospital monitoring does not include Gypsies and Travellers as an ethnic minority. We were also unable to extract information regarding children’s attendance, because the system set up for passing on information about these children to the outreach team broke down and, despite

talking to health outreach worker and the hospital records departments, it was not restored during the period of the research.

The following Table 4 contains information about the type of serious symptoms and traumatic incidents reported by the Gypsies and Travellers that we interviewed. A range of symptoms were described which included acute injuries and conditions, as well as acute exacerbations of chronic conditions.

<b>Adults' Symptoms or Traumatic incident per location</b>			
<i>NB: Each box represents one person's symptom or traumatic injury and shows that some people reported more than one episode.</i>			
	<b>Housed</b>	<b>Site</b>	<b>Roadsider</b>
1	Diabetes	Pulled stomach muscles	Broken arm
2	Severe asthma and kidney problems	Intermittent claudication, angina, COPD, bronchitis, emphysema and diabetes.	sprained ankle
3	Depression	Seizure	Hip problem
4	Gynae pain	Broken rib	Gallstones
5		Motorbike accident: broke both arms	Burns to foot
6		Chest infection	Fractured rib
7		Angina attack	

Table 4

The information about children (Table 5) was drawn from interviews with the parents, or a close family member involved in the episode. The entry entitled 'contamination' was, in fact, the result of a family staying on a poor quality site (outside the NHS Brighton and Hove boundaries), which proved to be a health hazard. The number of reports provided by roadsiders far outweighs those for children at other locations. Although the nature of this study makes it impossible to speculate on the significance of the finding, Beach (2006) found that children from two local authority Gypsy sites had higher levels of attendance and used A&E services more frequently than non Gypsy children housed in an area with a high deprivation score. She goes on to say that 'there are many Gypsy and Traveller families who have no permanent stopping place and experience frequent forced moves, often spending time in places that present even more challenges for child safety' (2006:883).

This is an area that would merit further investigation, particularly as it has proved impossible to access hospital data on this group.

Reports of children's symptoms by parents or close relative per location			
	Housed	Site	Roadsider
1	Severe vomiting	Fractured leg	Urine Infection
2	Cut head open		Possibly whooping cough
3			Asthmatic
4			Nappy rash, Eczema
5			Bleeding from the gut
6			Eczema
7			Contamination
8			Split back of head open
9			Tonsils out
10			Croupy cough in asthmatic child

Table 5

3. *Describe what action/treatment/referral occurred for Gypsies and Travellers who did use urgent care services.*

This provides an overview of participants' reports of the benefits of the action, treatment and referral, rather than a description of individual cases. This study was not set up to make any judgement on clinical competence.

Participants gave more detail when describing non-beneficial experiences and less when describing beneficial experiences. Therefore, we should not conclude that a larger amount of information about non-beneficial experiences indicates that a large number of experiences were non-beneficial. The data only provides a description of individual experiences and not an overall judgement on the quality of services received. The analysis does not distinguish between primary or acute settings and includes some information about the ambulance service.

Overall, participants reported a mixed picture, with some reporting good experiences of using local services.

*Non-beneficial experiences*

The factors that contributed to a non-beneficial experience can be divided into two main areas: administration of the service and clinical issues. Under administration, participants described being sent to the wrong place, poor attitude of staff/ discrimination, taking too long to be seen, lack of continuity of doctor or health

professional and being passed on elsewhere without proper explanation. Under clinical issues they described lack of full examination, lack of follow up, lack of change to treatment when the patient had reported that it was not working, pain was not taken seriously, lack of negotiation in treatment options, lack of/poor diagnosis, lack of early intervention, and – in one case – being given someone else’s diagnosis.

### *Beneficial experiences*

Factors that contributed to a beneficial experience were an appreciation of being fitted into a busy surgery and situations where participants valued being seen quickly and being treated patiently and fairly. Participants also valued receiving clinical treatment which took a family-orientated approach, ie. treating the whole family when necessary. Clinically, participants valued quick, decisive intervention and receiving the treatment, tests, or medication *they* felt they needed.

The indicators of beneficial or non-beneficial treatment were similar across participants from all locations.

### *Current health status*

We also asked participants to tell us how they felt now. Not everyone commented on this, but, of those who did, the worst health outcomes were reported by the housed population. This may not be surprising, as poor health may have been the reason why they chose to be housed. Roadsiders reported better health status on the whole.

#### *4. Describe what actions or other treatment options were taken by Gypsies and Travellers who reported recent serious symptoms and traumatic incidents but did not use urgent care services.*

The vast majority of participants did use either primary or hospital-based urgent care services, countering the perception that they didn’t use mainstream services appropriately. Only one adult treated themselves for a serious incident, but some others reported either using alternative treatments, or choosing not to use the medication prescribed.

5. *Determine the factors influencing Gypsies' and Travellers' decisions about where to seek help and from whom.*

There appears to be a well thought out approach to deciding where to seek help, based on the time of day, the severity of the symptom or trauma, previous experiences of the service and the amount of time it takes for a service to respond. When children had urgent or serious health needs, participants reported being more likely to access hospital services. If the episode happened late in the evening or at night participants would use A&E because the GP surgery was closed. Housed participants and roadsiders reported using out of hours services and, although generally helpful, in one case poor advice with no follow-up led to a child being taken to A&E.

A *small* number of participants – mostly those who lived on sites or by the roadside – used the hospital because they didn't have a GP, or because they felt the service was quicker, or the examination more thorough. One housed participant reported that they would go to the hospital 'just in case', because, if left at home too long, the person might become too ill.

Participants reported that they usually talked to family members in order to decide on the best course of action. Others, such as neighbours, might be asked to give advice, but the family or partner was the most trusted source of advice.

*Registering with a GP*

Ability to register with a GP, either temporarily or permanently, seemed relatively good on the whole. There was a report of an inability to register at a full surgery, but the participant had been given a telephone number for another surgery which accepted them. However, it must be remembered that there is an issue of literacy in this community and registration procedures may be difficult. There was one incident of inappropriate advice being given by a receptionist who said the participant could not change GPs, even though she had a problem with them.

Although most people were registered with a GP, those that were travelling may not have been registered with a GP local to the area where they were currently staying. The practice of using someone else's GP, or using a GP from an old address, was preferable to some people.

6. *Compare the average number and pattern of individual Gypsy and Traveller child attendances against the average number for the total population in Brighton and Hove.*

It was not possible to gather this statistical information because the BSUH NHS Trust does not collect monitoring information for the Gypsy and Traveller ethnic group. As part of the research process, members of the Steering Group contacted the Trust to encourage them to add the category to the current monitoring forms, but, due to administrative difficulties, this was not possible. Other ways of trying to get this data were discussed, but, unfortunately, the administrative support required to do this at the hospital was not available.

### **Other important things that people told us (emergent issues)**

This information comes under a number of headings (analytical themes), which provide more detail to support and elaborate the answers to the questions above. The information also identifies things that we did not originally plan to find out about. This is the advantage of using the participative research process, because it means Gypsies and Travellers themselves shape what it is important to know about their use of urgent services.

#### **a. Attitudes of staff - hospital urgent care services**

Gypsies and Travellers reported differing experiences, with the majority reporting poor attitudes, which were sometimes associated with poor clinical treatment.

*'Yeh. I bring my child to hospital. My daughter. And I told her (staff) she had a urine sample (infection) but they never looked into it. And I had to demand for a urine sample. And when I did get one after about 2 hours, she did have a water infection but I told them in the beginning... No we weren't treated fairly. Because if it had been someone else there they would have looked into it wouldn't they?'* (Interview 15R)

There were other criticisms of rudeness and discrimination on the basis of Gypsy and Traveller ethnicity and, in one case, religion, which was thought to result in poor service and treatment. Other reports of poor attitudes resulting in poor treatment included not taking health concerns seriously. One woman who presented at the hospital was asked by the reception staff if she'd had a heart attack:

*'I just said I don't know. That is why I am here. To find out what is wrong with me. And he told me to see my GP and asked me to leave the hospital...'* (How do you feel

about how you were treated?)... *Disgusted really... I would at least have liked them to have a look at me and refer me to a doctor to talk to. But I didn't get any of that.*' (Int 22 H).

Or rudeness:

*'So I went to the hospital, and they seen me straight away, and got in there: and when the nurse came round she told me that I was stupid, and that I am old enough to realise that you don't work-out without a professional person to help me.'* (Int 1S)

In one case even basic care was denied leaving patients to be sick on the floor:

*'So, we went over to the doctor's side, and they are still throwing up on the floor, and they didn't even give us a bucket, so we are trying to clean up their mess and they sent us home with nothing. (How did you feel about your treatment?) Disgusted. Like we was freaks. Like who were we strangers coming into their hospital.'* (Int 21H).

Others reported lack of proper follow up:

*'The treatment, if you could call it that, was a doctor turning up and saying "Oh you bruised your back, goodbye." He gave me some painkillers and that was it. Well I actually heard the rib break, and I still suffer with it now which is about 2 years later'* (Int 12 R).

This person felt that offhand treatment may not relate only to Gypsies and Travellers:

*'Well they did [know that the person was a Gypsy]. But that didn't have any significance: I think it was just the way that they are in A&E, you are OK – go home.'* (Int 12R)

Even if treatment outcomes were good, feelings of discrimination might have been caused by not explaining routine questions that were likely to be asked of the general population. One woman felt that questions were asked because of her background:

*'They asked me questions because I was young with two children, and they kept saying, like "do you smoke and do you drink?" but put in a way that I go off and leave my children, while I have a good time, do you know what I mean?'* (Int 24R)

Five of the fourteen reported that they thought the staff had good attitudes, and these often linked to their reports of good outcomes even in a case where a mistake in communicating diagnosis had been made:

*'No they were good to you... I had a kidney infection. And I went in. They saw me in about 20 minutes. And I went in, and they got it a little bit wrong...But apart from that I have never had any problems with them they have always been... whenever we have gone to them... we have always have always helped us. And they are basically good.'* (Int 1)

Fourteen people commented out of a possible total of twenty five and, of these, nine reported poor attitudes. This is a significant number and is in marked contrast to Health Commission emergency department survey data collected in 2008 where the general population rated performance (in relation to being treated with respect and dignity) highly.

*b. Attitudes of staff - General Practice*

Most people had little difficulty in registering with, or accessing, a GP but there were mixed experiences of using the GP services, with four describing positive experiences and eight negative.

GPs were criticised for not wanting to spend time with Gypsies and Travellers:

*'they want you in, they say like 'what's wrong' and you tell them and then you try and say what else is wrong with you, what other pains you think you're getting etc and they say "oh, you'll have to make another appointment to come back for that coz we haven't got time to discuss that now..." so now I know there's a woman GP at the surgery, I mainly ask to see her when I go there... coz with the others, how can I put it, you get like, it makes you think you know, do they know I'm a traveller? And they haven't really got time for you coz you're a traveller.'* (Int 10H)

There were other criticisms about GPs not listening:

*'With my doctor – she doesn't really listen. I know my body better than she knows me, obviously.'* (Int 22H)

or not knowing who they were and changing treatment without follow up.

*'And then she said to me, right, we are going to have to take you off your sick... and then she said to me – um – "you having tablets inside of your body is no good, pumping yourself with drugs, I feel that you are fit to go back to work" ...I thought I was treated unfair, because she didn't know none of my background, unlike my other doctor because he knew me like personally, and he knew all my business, and all my health and everything, and that other doctor didn't even know me. All she done was looked on the computer... She asked me to go there (psychiatric nurse referral), and*

*then she would follow it up and give me a call back. And that was 3 months ago and she never been in contact with me since.'* (Int 19H)

On the positive side there were examples of GPs accommodating roadsiders within their clinics:

*'The doctor at the time was quite good actually. It was quite a busy surgery, but they did fit me in quite well.'* (Int 13R)

and of being made to feel comfortable:

*'It was a nice lady doctor, really down to earth. Didn't make me feel upset about what I was having done or anything. She made me feel really comfortable and it was really nice.'* (Int 14R)

*'the GP that I am presently with is aware that I don't actually live at the address, that I have been using for many, many years. He understands that I am a travelling person and it's OK with him. He seems - it seems to be a case of their choice whether it is OK with them or not. But luckily with this present GP he is exceptionally good and very understanding.'* (Int 12R)

There was an example of the surgery sending out regular prescriptions so that the patient didn't forget her medication.

Twelve people, representing all locations, commented and, of these, eight reported poor attitudes. This is a significant number and is in marked contrast to Health Commission GP survey data collected in 2008 where performance regarding these negative issues was rated highly by the general population.

The vast majority of Gypsies and Travellers faced little or no discrimination when registered or accessing GP services. However, there was an isolated incident of incorrect information being given by a receptionist:

*'(Do you know you can change your doctor if you want to? If you are not feeling confident.) Well I didn't know. I didn't know. Because I did ask to change and they said no I couldn't change because I might have to see her if it was an emergency.'* (Int 22 H)

In one other case an example was given of the books being full and, although she was provided with the names of other surgeries, this appeared suspicious to the participant.

*'They said there was no room in that one so try the next one... Yeh. They gave me telephone numbers and told me to ring them, she writes it down... so I said can you tell me where they are... and when I went there they accepted me and seen me the same day... (Interviewer: I didn't realise GP surgeries got full though...They get full all of a sudden.'* (Int 1S)

c. *Attitudes of staff - ambulance services*

The Ambulance service was commented upon by six people and received a mixed response.

Some responses were very positive:

*'feeling bad all the time – always panicking and thought I was going to die, because I couldn't breathe, then I called them out. I called them out a few times and they have always been very helpful.'* (Int 22H)

but there were other criticisms regarding the length of wait.

One participant was unhappy that the police attended at the same time:

*'Well, I had an angina attack, phoned for an ambulance, waited for an ambulance or a paramedic to come and the police turned up and said there's a domestic going on here. (how did you feel about how you was treated?) Bad cos I was waiting for an ambulance to go to hospital and then a police car turned up.'* (Int 9S)

Also attitudes of staff in opposition to the person's view that they needed to go to hospital

*(When the ambulance turned up what kind of service did you think you got?) ...Bad, poorly, very poorly. They checked me over but I know that every time I have an angina attack I'm meant to go to hospital but he checked me over and said to me, well, now the pain's gone, you've got no need to go to hospital... Just keep using the spray he said... I did (go into hospital) on my own accord after that. I got me mate, I got a cousin to take me, that evening and they kept me in for 3 days.'* (Int 3S)

The other important issue appears to be that changes to services, such as a triage and assessment system, were not acceptable to people who wanted to be taken directly to hospital:

*'because she was having pains in her chest, and she was vomiting all the time. Very dehydrated. We phoned for an ambulance... and he was asking questions as they do. And he said there would be an ambulance on the way shortly. We waited and*

*waited, 45 minutes gone by and Mum is still not feeling well. So we phoned up again and he told me that he is sending a lady out to see us, just to ask us a few questions. And I said 'I don't want nobody to be coming and asking questions, we need an ambulance. He said 'well we have cancelled the ambulance we are using it for somebody else ' And with all that we had to wait 2 hours for an ambulance to come and pick her up and take her to hospital.'... And when we got, quite honestly, the doctor man said to her she was very dehydrated and she wouldn't have lasted any longer without fluids and anything.'* (Int 25H)

In this instance, when another emergency occurred, rather than call an ambulance the family took the child to A&E by car:

*'But at the time, with the bad experience that we had with my Mum previously, we thought it would be better to just jump in the car and take him straight through to A&E.'* (Int 25H)

Three participants out of the twenty-five who could have responded, identified areas in which they felt the attitudes of the service were not appropriate. Although this is not a large number it is slightly less favourable than the general population's performance rating given in the Health Care Commission (2008) report in respect of the ambulance service.

d. *Making the system work*

Participants described a number of ways in which they got access to health care to meet their needs. Some described ways of accessing GP services, such as using other people's addresses to get treatment, or using old addresses which better suited their needs:

*'I am not registered with any (local) GP. When I need a GP, which is very, very rarely, I usually go in as an outpatient. And everything gets sent back to who my original GP used to be from my home town. And that is the only time... I have only actually ever used them about three times in 20 years.'* (Int 13R)

They also used outpatients or accessed medical care at homeless centres:

*'so I just go to accident and emergency if I am badly hurt, but if I can find, like, a walk in centre I will go into them; or Morley Street in Brighton.'* (Int 1S)

There has been a suggestion that Gypsies and Travellers will take each others' medicine to save going to the GP. There was no evidence of this, although it may have been under reported. However there were three reports of using others'

medication because either their own supply of the same medicine had run out, or it was an over the counter drug like Paracetamol.

Gypsies and Travellers showed some knowledge of local services, although not everyone was aware of the GP service for the homeless. As people are moving from place to place, there is an issue about how to provide information about local services. One interesting example was given of another County where leaflets were disseminated by Park Rangers.

*'I had a notice sheet of all the available practices in the county of Somerset, starting with a local police, ambulance, out of hours, 24 hour call out general practitioners, the air ambulance and a midwife. All plainly printed and easy to see.'* (Int 18R).

Other good practice could include providing such a list on sites. However, whatever systems of dissemination are put in place it is important to remember that not everyone can read. Thought should therefore be given to other visual and oral ways of displaying the information.

There is reasonable knowledge and usage of NHS Direct by participants from all locations, but it is criticised for time it takes:

*'Yeh! They keep you on the phone the whole night. And then you have got to wait for someone to ring you back and by that time my girls would be dead. So we can't wait with their health.'* (Int 21H).

and also there is a perception that it is expensive if using a mobile phone:

*'It's a number you can dial if your child is ill and they give you a consultation and they can refer you to the hospital, but it is expensive.'* (Int 6R)

e. Moving on

Roadsiders spoke a lot about the implications of moving on in terms of access to services and, particularly, follow up treatment. Staying in one place, as in the housed population, is assumed to result in being registered with a local GP practice, which, in turn, is assumed to mean seeing the same GP who is familiar with the patient and can provide treatment in the context of their overall health profile. It also is assumed that being housed means the person gets to know and trust local services and is available for follow up care for hospital treatments. However, issues such as lack of continuity of GP provision were reported not only by those travelling but also by the housed population who felt that seeing different doctors meant a lack of proper follow

up and review. They reported needing to see the same doctor to renegotiate treatment if medication was not working. Moving from doctor to doctor, or from service to service, could lead to treatment that is never followed up or properly evaluated.

*'But they always give me the same medication. And it never ever makes you feel any different. It's is just the same. I have told them. I have said it to them. And they say just try it for another month and see how you feel. That's all they ever say to ya... I don't ever have the same permanent doctor, because this is the longest that I have been settled for a long time.'* (Int 1S)

Ongoing hospital treatment is disrupted when a roadside family is moved on. In one case arrangements were put in place by authorities to enable a family to stay in one place while being treated:

*'They (hospital) even rung up the Council. The Council rung them before we had to leave, and the Council rung them and they said that they would like us to stay, that we should be able to say until he got seen to. So they were helpful.'* (Int 4R).

Others appear to manage a degree of continuity when travelling by trying to keep the same GP so that other consultations whilst travelling are sent back to the original GP.

In other examples families will move areas in order to access services that they trust.

*'She (the hospital Doctor) is arguing with me, because she must know she has done wrong now. There is no need to send him back to Cambridge. I said 'well you are not doing nothing here' I says 'I want to send him back to Cambridge. 'I'll get an ambulance' (she said)*

*'No' I said 'me and my husband will take him'. We takes him into Cambridge and they sees to him straight away. They put him isolation, did tests on him straight away, and within 24hours they came back that it was contaminated.'* (Int 24 R)

[NB The hospital mentioned was not in the BSUH area.]

Moving on also has resonance for the way housed Gypsies and Travellers are beginning to use health services. They are registered with local GPs and are learning about the different types of health care provision but, as in the quote above, past experience will influence their decisions about which service to access.

f. Trust

Trust appears to be very important and plays an influential role in deciding where to seek help and from whom. Many participants trusted the service they received at the hospital, because it was more thorough than that provided at a GP surgery.

When explaining what advice they would give to someone with an urgent health problem this participant advised:

*'Just go to A&E, because they check everything. When you go to a doctor they just say you – you practically tell them what is the matter with you. But when you go to A&E they check everything. They take blood tests, check if you are OK, if you hurt they do X-Ray, they do everything to help you: if they can help you. But they make sure that they do it properly.'* (Int 1S)

There were many examples of how their trust was breached, for instance when participants felt they had not been listened to:

*'cos I've suffered from infections nearly all my life, you know when you got an infection and when you ain't and sometimes when you go there and you see a different doctor you do a water test and it don't always show up, then they say to you 'On no you haven't got an infection' and I say to them, 'I do know I have got an infection' and then they'll wait till about a week, till they get the results back..and by the time they got the results back, the infection's 10 times worsen than it was if they'd given the antibiotics there and then (so they're not really listening to what you're saying) No, I have also told them, they give me 200mg, 300 mg but in the past it doesn't work, I've got to go 500 mg every time.'* (Int 10 H).

and medication had been prescribed without proper testing:

*'Diabetes. Before I knew... because I was panicking because I couldn't breathe – it was in fact I couldn't get my breath – and I was going in and asking for what medication I wanted and all they were giving me was antibiotics. Loads of (Did he examine you? Did he look to see if you had any problem to give you antibiotics?) No.'* (Int 22 H).

Prescribing without examination was more likely to happen at a GP's surgery:

*'They (children) don't see the GP. Only I see the GP. I can get them medicine without seeing them. Which really is wrong because the GP has never even checked them. But I don't think they are even bothered to see them – they just write them the prescriptions.'* (Int 21H)

and participants were particularly critical of GPs asking them to describe the problem rather than conducting a physical check:

*'Whenever I go to my doctor, if I go to sort out – well me tonsils are hurting me – OK he asks me what is the matter with me and then he prescribes me the tablets, instead of him checking me to see if you are alright; and telling me what I have got I practically tells my doctor what I have got.'* (Int 1S).

Participants from all locations reported incidents of medicines that didn't work:

*'Not to change it a lot, sometimes if my asthma's really bad, then I have to go there (GP) and they give me steroids but they don't really help me a lot.'* (Int 10 H)...

and poor clinical treatment/operation outcomes:

*'First they sent her home and said there was nothing wrong with her, and then she complained with the pain, and then I had to take her back... And then when I took her back then to see the specialist, that was the second time. Then he decided to put her... first he never sent her for the X-Ray, but on the second visit he sent her for the X-Rays. He realised it was a chip out of the bone of her knee cap.'* (Int 2 S).

One particularly disturbing situation was of a twenty three year old woman who had attended A&E with abdominal pain and who then had a hysterectomy:

*'Me and my husband discussed it and we felt that there was no... because I had been examined by a doctor – and they said that they think that was the cause of it (pain) – having a drop womb – I had no choice but to have it done.. When she (GP) wrote me the letter, I got the reply quite quickly – within a couple of months – I was up there and had my hysterectomy done (And how are you feeling? Do you)... I am still the same, in the same boat that I was before I had it done... Just recently I had an MRI scan done, which I feel that they should have done in the first – beginning – before I had my hysterectomy done because then I would never have had to have it done really.'* (Int 20H)

Belief in the safety or efficacy of the treatment is also important and there is evidence of participants refusing to take medication because they don't believe it is good for them or their children:

*'XXX has been diagnosed ADHD two weeks ago. But he did say to me 'how do you feel, how about medication for xxx?' And I said 'Yes. I would give it a try' and then he said 'I am going to give you a prescription for Ritalin' and then I did say to him – 'look I have heard about that – I don't really want to give that to my child, is there something else?' And he said 'Well try it with him for a couple of weeks' I did ask*

*him what the long term effects were, and he said it stunts their growth, like, over a period of time. But then, since that, I have not got the prescription and I have not got xxx no tablets. I don't want to be giving the child medicine and that.'* (Int 19 H).

In another example an alternative remedy called the 'Black Cure' is used on a child's eczema because it was trusted and thought to work better:

*'My brother's little girl, xxx, she had eczema, it's a black cure you get in Ireland, and it's common... You rub it on the skin but you are not supposed to wash the baby. Till 10 or 12 days and it's cured the skin of eczema I have faith in it cured. (Had you used any other creams from the doctors before you used that?)... I tried aqueous creams I tried different ways, Timodine, I have tried Canestan Cream, and not a cure with that.'* (Int 7 R).

However, once trust in the service or practitioner is established, members of the family will recommend that service to family members and others:

*'I took him up 'cos of the one being ill, and the other son and me nephew – and he seen them straight away and given them antibiotics and it was very good... And me grandbaby. And we sort of known it was whooping cough, but we didn't have nothing to really say... and they done tests for everything, and we could tell by the sound of it as well. We was there and we knew. So they treated everybody who we brought. No matter who goes up there now, we give - they gives our name and they will give them the whole two weeks of antibiotics, to make sure.'* (Int 4R)

Participants also describe bringing other family members from other areas and countries back to this provider:

*'In the Holland Hospital... he went in on Friday and come out on Saturday. And he rang me on the Sunday, and I asked him and he told me that he was still bleeding and me son – my oldest son put him on a plane, and they got on Amsterdam at 10 and he came off here at 10 o'clock at Gatwick and I lifted him up at Gatwick and I brought him straight to A&E (in Brighton).'* (Int 23 R)

As a result of hearing our participants' less positive stories, we became aware that very few people were aware of NHS complaints procedures.

*'...no one ever explained to me that I could put complaints in... so that's why I never put anything in... If I'd known I would have done it.'* (Int 10H).

The ability to complain is often dependent on filling in forms and therefore being able to read and write. Systems for supporting Gypsies and Travellers who wish to complain should be considered.

g. Alternatives to mainstream treatment

There were few examples, but they ranged from not taking prescribed medication to taking traditional remedies, such as the Black Cure described above, or remedies suggested by others. In the following example a remedy had been offered as immediate treatment for a burn from boiling water, which fortunately was not acted upon.

*'(a neighbour) said put jam on it to sizzle my foot... I put it in cold water and went up to accident and emergency.'* (Int 17 R).

Others described self help strategies:

*'I am still upset on my own: because they don't know what is wrong with me. They have given me tablets for this – thinking it is for that – take this tablet to make that one work – but it is not helping me: I think that the tablets are doing more harm than good really... I tried cutting certain foods out and joining the gym up to do a bit of exercise, because it got on top of me that I had put a bit of weight on as well. But I can't even do that anymore. I have got my own gym and I haven't used it for over a year now because I am so much pain – and I have got four kids as well.'* (Int 20 H)

or homeopathic/herbal remedies:

*'I usually use my own homeopathic herbal medicines and that. I find that they work equally, if not a lot of times better, than... Well I treated my own hand and that. With antiseptic. And I put my own dressings on, and I sort of made my stitches and that with Gaffer tape and stuff. And it worked.'* (Int 18R)

These were often used because of a lack of belief in the treatment prescribed, the potential side effects, or the wish to be independent of mainstream medicine:

*'No. I had a condition, which is called an anxiety disorder or panic attacks, which come and go, and I have been offered treatment for them but I have chosen not to take the treatment because of the type of medication they offered. (You have been to your GP to talk about this?) Nope. I don't like taking tablets. Period. Even when I need pain killers, I choose not to unless it's crucial.'* (Int 12 R)

h. Time

Time was an important issue for participants, both in terms of the time of day that the episode occurred and also the time it took to be seen. Site and roadside participants

reported using GP and out of hours services, but sometimes A&E because they would be seen quicker:

*'I prefer to go to the A&E because it's is quicker. If you go down Morely Street you are sitting from... well if you get in there at half-nine you are sitting there till 12 or 1! Whereas if you go to the A&E you are seen in... you are in and out in half an hour. You are in and out the whole lot inside half an hour. I prefer to go to the A&E even though my doctor says Morley Street, because it is a quicker service.'* (Int 6 R).

Not all participants did this and one Roadside participant reported using the out of hours service:

*'I didn't call him because I was so ill. I had no recollection of him being there. My family got the doctor in. I was that ill I weren't even conscious and that... Yeh. Yeh. The fact that he came out in the middle of the night and everything.'* (Int 18 R)

*i. Interaction with other services*

Improvement in health outcomes should be seen within the broader context of social determinates of health, which involve contributions from a number of other services, such as council, education and police services.

One participant described having to balance follow up health appointments with schooling and getting in to trouble for poor attendance:

*'Yes, they are under Doctor xxx, but then he is on certain days on which they can't go because they are getting in trouble in school; so we have to rearrange it. And when we are in the hospital the school don't believe we are there, so we are trying to rush the appointments, you know, cancel appointments because otherwise we are getting into trouble in school'.* (Int 21H)

Another participant described an episode when the ambulance was called and the police turned up at the same time. Although this might have been because of difficulties on the site, it was considered discrimination by the participant and their family.

One positive example of cross agency working was the report of the council being contacted by A&E staff to enable a patient to remain on an unauthorised site while undergoing follow up treatment.

## **9. What does it mean for services for Gypsies and Travellers?**

Gypsies and Travellers appear to have very clear and logical strategies for accessing particular services, which contradicts the perception that they use hospital services inappropriately. This is supported by the early research findings, which contest the general notion of inappropriate attendance at A&E (Walsh 1995). The literature reveals a number of reasons for the general population choosing to use hospital urgent care services; these include a feeling that the treatment provided in hospital is better than that provided by GPs and that it is more convenient and accessible (Walsh, 1995, Murphy 1998, Sempere-Selva et al, 2000). These reasons are similar to those given in our study, where preference is given to hospital care on the basis that there is immediate access to diagnostic tests and the clinical assessment provided is more thorough. The preference for hospital is also based on the accessibility of a 24-hour system with less waiting time than a GP surgery.

National and local changes are making urgent care services more comprehensive by offering a 24/7 hospital-based service, which is easily accessible and with appropriate health care to match the type of symptom or injury. This provision will provide the onsite access to diagnostic tests valued by the Gypsy and Traveller population. However, issues of follow up of emergency care and after care of non emergency conditions noted at initial assessment will require resolution as exemplified in Lawrence's (2007) study. More significantly, in our study we found frequent examples of lack of follow up care for those accessing hospital and GP services alike, and these were reported by both the housed and travelling community. Some of these examples were due to fragmentation of provision, eg. by being seen at the hospital and then moving on, or by being seen on site by the ambulance team. Worryingly, there were also reports of lack of follow up in the housed population which were attributed to being seen by different Doctors in the same surgery with no real ongoing review of treatment effectiveness.

Whilst new local comprehensive services are a way forward, particularly for those who are travelling, there is the issue of how to maintain an overall picture of a person's health profile across a range of primary care providers. Someone who is travelling could access services in a number of different counties and if they register with a GP service as a temporary resident the records of these consultations may never be collated in one place. Therefore treatment, especially for exacerbations of chronic illness, is not prescribed within the context of the person's overall health profile. The Gypsies and Travellers in our study provided evidence of a number of approaches to maintaining GP continuity within their travelling lifestyle such as using an original GP in their 'home' town as a forwarding address for reports from

consultations in other places. However a national solution is required and other models of maintaining continuity of service provision, such as that used by the maternity services, could be explored. One local initiative is the trialling of patient-held records through the Pacesetters programme<sup>5</sup> in Hastings and Rother.

Our study shows that the large majority of participants did use either primary or hospital-based urgent care services, but there were some reports of self treatment and of seeking advice from other members of the community. This type of action could result in sub optimum outcomes and it is suggested that first aid training could be given on sites, for instance Red Cross training, and that those trained could carry first aid kits if they were highly mobile. Similarly, when response time before attendance is crucial, such as in cardiac arrest, Cardio-Pulmonary Resuscitation (CPR) training could be provided to someone trusted by the community.

One of the major factors determining decisions about where to seek help and from whom, was the Gypsies' and Travellers' previous experience of the service and the level of trust it inspired. As demonstrated in our study, there are a number of factors that need to be taken into account to ensure that this service is acceptable to and trusted by Gypsies and Travellers.

Many of the criticisms made in this study could apply to the general population but it is clear from an analysis of the patient survey reports presented in the Health Care Commission (2008) that a higher level of dissatisfaction with GP services was reported by the Gypsy and Traveller population in terms of waiting times, being listened to, being given enough time to talk through problems, being treated with respect and dignity and having trust in the Doctor. Similarly, the BSUH NHS Trust emergency department general population data showed that the care received by the ambulance services was rated very highly, which is contradicted by the data in the Gypsy and Traveller study. Interestingly, the Gypsies' and Travellers' views regarding waiting in the emergency department appear to be slightly more favourable than in the general population, but very similar in terms of having had a generally good experience. However, it should be noted that the patient surveys carried out by the Health Commission recruited low numbers and this, combined with an over ninety percent response from the white ethnic group, could be criticised for being unrepresentative of the general population. It certainly highlights the need to ensure that all groups are properly included in consultations. The very small numbers in the Gypsy and Traveller population means that their response will be

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<sup>5</sup> The Pacesetters programme is a partnership between local communities who experience health inequalities, the NHS and the Department of Health. Working with Strategic Health Authorities (SHAs) and Trusts, the overall aim is to deliver equality and diversity improvements and innovations.

hidden within the majority view, so it is important to hold separate consultations for Gypsies and Travellers and other marginalised groups.

Staff attitudes played a big part in determining whether Gypsies and Travellers felt they had a good experience and, whilst there was a lot of good feedback in this study, there were also some instances where discrimination was reported. Gypsies' and Travellers' fear of hostility and prejudice could affect the way they used services (Cemlyn et al 2009). If staff attitudes are thought to be good then treatment outcomes are often well evaluated and participants seemed more likely to tolerate minor mistakes, or the inability to immediately diagnose problems.

Health professionals need to know more about the culture and beliefs of the Gypsy and Traveller community (Cemlyn et al 2009). It is suggested that training could be offered to staff in all frontline health services so that they can better understand the Gypsy and Traveller way of life and challenge their own or others' assumptions. In our study it became clear that Gypsies and Travellers were unaware of the complaints system and, although they are unlikely to complain due to lack of literacy, or fear of recriminations, a means of providing a supportive advocate scheme should be investigated.

Throughout the analysis it became clear that taking a more family-orientated approach to delivering health care might prove beneficial. Unless the patient lacks capacity, or is a child, health care systems deal with the individual. Within the Gypsy and Traveller culture there are close family bonds, meaning that a family will associate with a particular trusted health care provider and the study provided evidence of those travelling moving back to that provider. Gypsies and Travellers will often attend appointments together for moral support, which provides an excellent opportunity to work with the whole family on health promotional activities such as screening and immunisation. Similarly, taking an extended family approach can lead to health professionals being welcomed on site to deliver services. Goward et al (2006) refer to the lack of fit between health care services and the Gypsy and Traveller community. They observe that "mental health providers are generally trained to work with individuals, not whole communities or systems. Such individualistic models of understanding and working with mental health problems do not fit easily into the preferred ways of working as outlined by Gypsies and Travellers." (2006:324)

In order for people to access services they need to know they exist; therefore, creative ways of disseminating local information about local services should be put in place. Similarly, in order for services to reach Gypsies and Travellers they need to

know where they are, both on authorised and unauthorised sites. Outreach workers within organisations like FFT provide a vital liaison role between services and the community but, more pragmatically, providing signage to official sites would enable urgent services to find them more quickly and also posted information would arrive more effectively.

Health professionals need to know about Gypsies and Travellers on site and their wish to take up services. Enhanced communication can lead, as has been the case as a result of our study, in doctors and nurses coming onto sites to deliver immunisations. The role of the outreach worker is crucial in this type of situation and this research has demonstrated that a more proactive outreach role can be achieved.

We gathered information from Gypsies and Travellers who were travelling (roadsiders), on authorised sites and who were housed. However, the housed participants reported worse current health than either of the other two groups. This is consistent with recent research indicating that housed travellers are more likely to be exposed to “more direct and immediate hostility focused on their ethnicity or lifestyle.” (Cemlyn et al 2009:v). .

Finally, whilst this study has concentrated on urgent care it has become clear that health services do not exist in a vacuum and wider determinants of health must be taken into account. Improvement in the health of Gypsies and Travellers involves the co-operation of a range of other agencies, such as the council, education services and the police force. One example of this is the lack of authorised accommodation in Brighton contributes to the national shortfall in accommodation for Gypsies and Travellers who do not wish live in conventional housing (Cemlyn et al 2009).

## **Recommendations**

The following recommendations arise from the findings of the study and are structured into recommendations for local and national action:

NHS Brighton and Hove local action:

- *Monitoring the implementation of the new urgent care system with regard to determining improved levels of Gypsy and Traveller confidence in clinical assessment and treatment and satisfaction with the length of wait to be seen.*
- *Monitoring the experiences of those using the new urgent care service to see how issues regarding follow up and after care are managed.*

- *Delivering culturally appropriate provision to staff in all frontline health services, so that they can better understand the Gypsy and Traveller way of life and challenge their own or others' assumptions.*
- *Improving communication between the health care providers and Gypsies and Travellers to engender confidence in agreed treatment options.*
- *Strengthening the role of the outreach workers to support the housed population to improve dialogue with GPs and other health professionals to achieve ongoing review of treatment effectiveness.*
- *Strengthening the role of outreach worker in terms of liaison between health professionals' awareness of Gypsies and Travellers living on local sites and their health care needs.*
- *Promoting a family and community approach to delivering services to Gypsies and Travellers, which could provide opportunities to work with the whole community on health promotional activities.*
- *Strengthening links with the Gypsy and Traveller community to explore ways to reduce response time for serious injury and illness by offering First Aid and Cardio Pulmonary Resuscitation training, with the potential for providing first aid equipment to highly mobile groups.*
- *Increasing Gypsy and Traveller knowledge of local services using creative ways of disseminating information. One suggestion is to provide a board on local sites outlining local service contact details, including Patient Advisory and Liaison Service (PALS).*
- *Provision of accessible information about the changes in service provision to reduce misunderstanding and enable full uptake.*
- *Promoting awareness of the complaints system and seeking ways to provide an advocacy system.*
- *Ensuring that all groups are properly represented in consultations by holding separate consultations for Gypsies and Travellers and other marginalised groups and involving them in designing local services*
- *Increase ability of service providers to find authorised sites. Providing signage to authorised sites would enable urgent services to find them more quickly and allow posted information to arrive more effectively.*

Recommendations for action at national level:

- *Investigate innovative ways of maintaining GP continuity within the travelling lifestyle. Newly announced government proposals, which change the requirement for registration with a local GP, may enable those travelling to stay registered with a single GP, thereby maintaining continuity. However, a*

*system whereby health records could be shared would also be required. One possible suggestion is the use of patient-held records, such as those being investigated in a pilot project which is part of the Hastings and Rother Pacesetters programme.*

- *Consideration should be given to ways of fostering trust and understanding within the Gypsy and Traveller community by:*
  - *Encouraging members of Gypsy and Traveller communities to become involved in designing local and national services.*
  - *Encouraging members of the Gypsy and Traveller population to consider becoming members of the NHS workforce.*

## **10. Did we miss anything?**

The main limitation of the study was the size of the sample which, although within our original estimation of between seven and forty participants, is still small. The study was conducted within the NHS Brighton and Hove catchment area where Brighton does not have a permanent site at present. This meant that potential participants were highly mobile and less easy to recruit. Additionally, the data collection got off to a slow start, which meant that we missed a large number of people who visited the outlying areas during the summer holidays.

Although we were able to report on a wide range of serious symptoms and traumatic incidents that required urgent care, we feel that information about mental health problems was probably under-reported. Goward et al's (2006) study confirms that Gypsies and Travellers experience significantly higher levels of anxiety and depression than the general population. Cemlyn et al (2009:iii), in their review of the inequalities experienced by Gypsy and Traveller communities, go further and indicate that "high rates of anxiety and depression and at times self-destructive behaviour (for example suicide and/or substance abuse)" exist. The lack of reporting in our study may be due to the stigma that is still attached to mental health disorder in the Gypsy population.

The other areas that Gypsies and Travellers are often reluctant to talk about are Cancer and Sexual Health (Van Cleemput et al, 2007). There were no reports in either of these areas, although the focus on 'urgent care' might have precluded participants talking about them. One participant spontaneously complained about a lack of dental services which was something that we had not thought to include in our interview schedule.

Participants did talk about childbirth experiences but we were not able to include them as they were not recent. However, we know statistically that there are higher miscarriage and stillbirth rates amongst the Gypsy and Traveller population (Parry et al 2004) and, anecdotally, that there are problems with follow up for recurrent miscarriages and problems in being admitted when in labour.

Although not a limitation of the study, it should be acknowledged that Brighton has a well developed set of services such as a specific GP service for homeless people, although other areas served by the NHS Brighton and Hove in West Sussex do not. This does not affect the findings of the study, which reflect this mixed provision, but it does limit the transferability of the findings to other areas as urgent care provision will differ.

Our study excluded New Travellers and Occupational Travellers, who have opted for an alternative lifestyle but are not of the same culture and are considered to be social groups under the terms of the Race Relations Act. However, we feel that research into New Travellers' health needs should also be undertaken.

## **11. Conclusion**

Our study shows that the large majority of participants did use either primary or hospital-based urgent care services, but their experiences were often sub optimal. Gypsies and Travellers, similar to the general population, appear to have very clear and logical strategies for accessing the particular services that they do, which contradicts the perception that they use hospital services inappropriately. However, their experiences of using the services are less favourable when compared with data from the local general population.

National and local changes will make urgent care services more comprehensive by offering an easily accessible 24/7 hospital-based service, which will provide many of the benefits valued by Gypsies and Travellers. However, issues of potential lack of follow up of emergency care, as well as after-care of non-emergency conditions noted at initial assessment, remain. These concerns will require monitoring to ensure resolution. Action is also required to improve GP's follow up care for the housed population, which was attributed to a lack of ongoing review of treatment effectiveness.

Although a large number of Gypsies and Travellers reported poor experiences, none had formally complained. This was due to a lack of awareness of the complaints procedures, but also possibly due to the fatalistic view that nothing would change

and suspicion of recriminations. Patient Advocacy Liaison Services have an important role in providing support to this group.

Gypsies and Travellers' health overall is poorer than others' in socially deprived areas and they have poor health expectations. Therefore services need to be culturally sensitive and respond to their lifestyle needs in order to increase trust and enhance uptake. Measures such as taking a family and community approach to delivering services to Gypsies and Travellers could lead to opportunities to enhance trust and work with the whole community on health promotional activities, like screening and immunisation. Developing relationships with the community could lead to health professionals being welcomed on site to deliver services. Working together with the community to enhance health outcomes could also lead to offering training in First Aid and Cardio-Pulmonary Resuscitation to members of the community.

Many reports highlight the efficacy of employing specialist health outreach staff to work with Gypsies and Travellers, rather than relying on health staff for ethnic minority groups and homeless people (Cemlyn 2009:58). This research highlights the important work that has already been done by FFT outreach workers, who have the knowledge and the credibility within the community to advise people about services and support them in dealing with health issues. This research has shown that the outreach role is effective, but could become even more proactive. However as Cemlyn 2009 points out, there is a need for dedicated monies to support continued improvements because if health outreach workers are seen as part of short term projects there is a risk that health improvements are lost when they finish.

Urgent care services need to be seen within the context of the social determinants of health. Improvements in the health of Gypsies and Travellers involve the co-operation of a range of other agencies, including the local authority, education services and the police force. Practical initiatives, such as working with the local authority to signpost sites so that emergency services can reach Gypsies and Travellers more quickly and enabling patients requiring follow up care to stay in the area, could lead to improved outcomes.

In order to achieve multi-agency working, barriers need to be broken down and Gypsies and Travellers need to be involved in designing and delivering services. This approach is akin to the Declaration of Alma-Ata (WHO, 1978) which stated that people not only had a right, but also a duty, to participate in and plan their own care. Many of these values are strengthened in the World Health Report (2008) on primary health care. They are further reinforced by the acknowledgement in the final report of

the Commission for Social Determinants of Health (CSDH, 2008: chapter 9) that improvements in health are based on social empowerment.

Using a participatory approach, which fully involved Gypsies and Travellers in research design and operation, has led to a greater understanding of the experiences of the community and opened up a dialogue between health and other services. It has resulted in normally suspicious Gypsy and Traveller families opening their doors to researchers and genuinely believing that change could come about as a result of their voices being heard.

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# Appendices

## Appendix 1

### Data sources mapped against specific outcomes

Specific Outcomes	Urgent services department data	Interviews	Comments
Describe the range of symptoms/traumatic incidents reported by total Gypsy and Traveller population		<ul style="list-style-type: none"> <li>○ Gypsies and Travellers</li> <li>○ Outreach worker</li> </ul>	Based on a 20% inclusion rate I anticipate a minimum number of 7 Gypsy and Traveller participants and a maximum number of 40 participants. The sample will be accessed at 3 monthly points in the year and therefore follow up interviews may be required if participants are interviewed immediately following an acute injuries/ symptoms.
Describe the symptoms/ traumatic incidents that bring individual Gypsies and Travellers to use urgent services	To determine presenting symptoms through audit of data collected by department		Compare the number of Gypsies' and Travellers' 'attendances' against number of total 'attendances'
Describe attendance patterns of gypsies and travellers when using urgent services	To determine the number of times each individual is seen through audit information collected by the department).		<ol style="list-style-type: none"> <li>1. Compare the average number of individual gypsy and traveller attendances against the average number for the total population.</li> <li>2. Chart the incidence of attendance against times of day and months of the year and compare with total population trends</li> </ol>
Describe action/treatment/ referral for Gypsy and Traveller population attending urgent services	To determine action/ treatment/ referral from audit information collected by the department		
Describe action/treatment/ referral for Gypsies and Travellers who did not use urgent services		<ul style="list-style-type: none"> <li>○ Gypsies and Travellers</li> <li>○ Outreach worker</li> </ul>	
Determine the factors influencing Gypsies and Travellers decisions as to where to seek help and from whom		<ul style="list-style-type: none"> <li>○ Gypsies and Travellers</li> </ul>	

## Appendix 2

### Definition of the terms 'Gypsy and Traveller'

The term 'Gypsy and Traveller' used in this study encompasses both Romany Gypsies and Irish Travellers, each with a separate ethnic identity and sharing many aspects of a common cultural identity as traditional travellers. Our study excludes New Travellers and Occupational Travellers, who live in this way for a variety of reasons but are not of the same culture and who are considered to be social groups under the terms of the Race Relations Act,

The UK's 300,000 Gypsies and Travellers have lived, worked and travelled throughout the UK for over 500 years. Gypsies and Travellers form rich, varied and diverse communities and include:

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

Some members of these diverse groups still live a nomadic existence; others may live on authorised sites or within housing. Scottish and Welsh Travellers are not protected by race equality legislation and would require a test case in order to be identified as ethnic Travellers. New Travellers, Bargees, Showpeople and Circus People are identified as Occupational Travellers. Many New Travellers are into their third generation now. The New Traveller community is a very diverse and tolerant community which has absorbed people who might have mental health problems, as well as ex-service men and women.

## Appendix 3

### Information sheet

#### **Research into Gypsies' and Travellers' use of urgent care services**

**What is the research for?** Brighton and Hove Primary Health Care Trust want to improve health services to people from the Gypsy and Traveller community.

**What will we be trying to find out?** We want to look at the how Gypsies and Travellers in Brighton & Hove use urgent services such as Accident and Emergency at the hospital, and also find out about times when Gypsies and Travellers report/experience symptoms and injuries but do not access urgent services.

**Why have I been given this information sheet?** You have shown an interest in what we are doing and we hoped that you might be willing to take part in the research project. We want to give you as much information as possible to help you decide.

**What would I have to do?** We would like you to tell us about any recent serious illness or injury. A researcher would come to your home, or wherever you choose, and talk to you for up to an hour. If you need to travel for this we will reimburse your travel expenses. We would record the discussion on tape recorder, but it would only be heard by the researchers and no one else would know what you had said unless we were legally bound to disclose it. The researchers who talk to you are from the Gypsy and Traveller community and they are specially chosen and trained so that what you say will be private.

**Do I have to take part?** You do not have to take part in the research if you don't want to. Even if you decide to take part, you can stop taking part in the research at any time without giving a reason. You can also say if you do not want to answer some of the questions.

**Who will know what I have said if I take part?** What you say will only be heard by the researchers. If you take part, we will tape-record the discussion but nobody, apart from the researchers, will know that it is you who was talking. Sometimes we like to use quotes in written or spoken presentations and we will ask you for your written consent to do this. Of course, when we write about your opinions or experiences in our reports we will not use your real name. None of the people you live with, nor anyone else, will know that it was you who told us what we have written

about unless you tell them. We will keep the tape-recording of our discussion in a locked cupboard. When we have finished the project we will destroy the tape-recordings.

**Will taking part affect me in any way?** Taking part won't affect your physical health in any way. However, you may have had some difficult experiences and so you may get upset if you choose to talk about them. If you do get upset, we will be understanding and offer support. Also, if you want us to, we will put you in touch with other support that is available.

**Will I benefit from taking part?** We would like to thank you for your time and involvement in the research by providing a £5 supermarket voucher. Also – although it may not happen straight away – the Gypsy and Traveller community as a whole will benefit from finding out about their specific needs in order to improve health services.

**Will I hear about the findings?** At the end of the research a report will be written and we will arrange to talk about the findings in a local centre. No one will know that you were involved in the research, or know what you said, unless you choose to tell them yourself.

**Who is doing this research study?** The research is being done by researchers at the University of Brighton, helped by two researchers from the Gypsy and Traveller community. The research is being led by Professor Valerie Hall (University of Brighton). If you want to know more please let Professor Valerie Hall or Sally Burnett at FFT know. Valerie's telephone number at the University of Brighton is (01273) 644015.

If you are unhappy about anything in the research you can talk to Phil Cotterell at the University (01273 644599) who is independent from the study, or, if you would rather talk to someone at FFT, please ring Zoe Matthews whose telephone number is (01273) 234777.

## **Interview schedule.**

### ***Gypsies' and Travellers' use of urgent care services***

#### ***Interview schedule – indicative areas***

##### **Icebreaker Question**

How long have you lived here? How long on site/road?

**Please can you tell us about any serious illness or injury that has happened to you or your children in the last three months?**

Prompt areas: when did it happen, how did it happen, has it happened before?

**What did you do about this illness or injury?**

Prompt areas: used NHS services and if so which ones and where?

If did not use NHS services describe what other support or action was sought and from whom?

If did not use NHS services what were the reasons?

Probe areas: cultural beliefs, cultural norms, reception by NHS staff (a previous negative experience etc.)

**How did you decide what to do? What options did you feel you had?**

**What happened next?**

Prompt areas: describe any NHS treatment, referral and follow up.

If offered planned referral and follow up, describe what happened. Was NHS treatment, referral and follow up supplemented by other treatment or support?

If NHS planned referral and follow up were not used what were the reasons?

If did not use NHS services, describe any other support or action that was sought and from whom.

Probe areas: cultural beliefs, cultural norms, reception by NHS staff

**How did you feel about what happened to you when you were trying to get help for a serious illness or injury?**

**What would you have liked to happen?**

**Given your own experience, what advice would you give to a GYPSY AND TRAVELLER friend/family member who faced a similar, serious symptom/traumatic incident? What would most help them?**

**How is your health generally and how is it now?**

**Is there anything else you want to tell us?**

**Thank you**

## Appendix 4

### Participant Consent Form

#### Research into Gypsies' and Travellers' use of 'Urgent Care' services

- I agree to take part in this research which is to identify Gypsies' and Travellers' use of 'Urgent Care'/A&E services.
- The researcher has explained the purpose of the study to me and what they want me to do.
- I understand that any confidential information will be seen only by the researchers unless they are legally bound to disclose it.
- I agree that some of the things I say may be used in a report but that I will not be able to be identified as the person who said it.
- I understand that I can withdraw from the research at any time or I can say that I do not want to answer one or some of the questions
- I have been asked if I am willing to have the interview recorded and it has been explained that the recording will be destroyed when the project is finished, and I agree.

---

Name of Participant

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Date

---

Signature

---

Researcher

---

Date

---

Signature



Friends, Families and Travellers



**University of Brighton**

**NHS**  
*Brighton and Hove*