HEALTH NEEDS ASSESSMENT: CUMBRIA GYPSY TRAVELLERS

November 2009

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Photographs by kind permission of the Appleby Fair
Multi-Agency Strategic Co-ordinating Group and

NHS Cumbria would like to thank Richard O’Neill and Louise
Wannop for co-ordinating the data collection for this project.
Grateful thanks also to all the Travellers who gave up
their time to support this work.
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Executive Summary

1. These findings confirm the evidence from other studies that Gypsies and Travellers have significantly poorer health status and more self-reported symptoms of ill-health than both other UK resident English-speaking ethnic minority groups and economically disadvantaged white UK residents.

2. The prevalence of mental health and wellbeing problems within the Travelling community in Cumbria appears to be considerably higher than in both the overall population of the North West Region and in England as a whole.

3. There is a wide disparity between immunisation uptake in the settled wider population and the Travelling population in Cumbria. There is a particular resistance to the MMR vaccination amongst Travellers.

4. As an ethnic group, Irish Travellers in Cumbria experienced the greatest health problems and are the least likely to be registered with a GP or use healthcare services. All the Irish Travellers interviewed were living on unauthorised sites at the time of the study.

5. Barriers to healthcare access were experienced, including: reluctance of some GP surgeries to register Travellers with no permanent address or postcode; practical problems of access whilst travelling; complex and variable appointment systems; mismatch of expectations between Travellers and healthcare staff; interruption of treatment as a consequence of travelling or being moved on/evicted.

6. There were also a considerable number of references to positive experiences with healthcare staff in Cumbria; GPs (and other healthcare staff) perceived to be understanding, sympathetic and trustworthy are highly valued and well-known throughout the Travelling community in Cumbria.

7. Although the percentage of Travellers registered with a GP in Cumbria is relatively high (86 per cent) and relationships with healthcare staff seem generally positive, over half (54 per cent) of the Traveller sample was unwilling to identify themselves as Travellers to their GP because of fear of discrimination and negative stereotyping.

8. Although the percentage of Travellers registered with a GP in Cumbria is relatively high, only 53 per cent of the health professional sample reported known contact with Travellers. Given that 54 per cent of the Traveller sample would not identify themselves as Travellers when registering with a doctor, it seems reasonable to assume that a considerable number of health professionals will be unaware that they have Traveller patients.
9. Health Professionals who had known contact with Travellers predominantly identified them as Travellers by their address i.e. authorised/unauthorised site, caravan/trailer, or no fixed address. However, over half (58 per cent) of the Traveller sample live in bricks-and-mortar accommodation.

10. The commonly-held perception that most Travellers live in caravans or trailers, combined with the fear of identification expressed by many Travellers, may well contribute to the perceived ‘invisibility’ of housed Travellers to health services and to local authorities. This is a concern when there is some evidence of specific health need amongst housed Travellers in Cumbria.

11. Travellers did express specific concerns about their health as an ethnic group, particularly in relation to high levels of anxiety and stress, smoking, alcohol and drug use.

12. There was a strong element of self-reliance and stoicism in the face of ill-health which may underlie a tendency to denial and delay in presentation for healthcare and/or screening.

13. Men in particular take pride in being seen as fit and strong and may deny illness as a sign of ‘weakness’ as well as for purely practical reasons.
1. Introduction and Background

Estimates of the Gypsy Roma and Irish Traveller populations vary widely due to both the nomadic lifestyle and the fact that there is no ethnic coding for these groups included in the national census. There are also far more Gypsies and Travellers resident in housing than on caravan sites and their needs are often overlooked as they are effectively invisible to ethnic monitoring (O’Neill, Health Service Journal, 2008). Roma Gypsies and Irish Travellers have their own languages, cultural identity and traditions.

Evidence indicates that Gypsies and Travellers have significantly poorer health status and more self-reported symptoms of ill-health than both other UK resident English-speaking ethnic minority groups and economically disadvantaged white UK residents.

While there are no national morbidity statistics, it is acknowledged that the life expectancy of Gypsies is 10-12 years below that of the settled population. One in five Gypsy and Traveller women has experienced the death of their child compared to less than 1 per cent of the settled population, and the rate of miscarriage is almost twice that of the settled population.

Traditional attitudes to health care by the Travelling community are recognised as being characterised by a belief in self reliance (and reliance on the extended family) with a general suspicion of health services. (Ormiston Children & Families Trust and Cambridgeshire Community Services, 2008)

Local consultation with the Gypsy and Travelling communities in Cumbria has revealed that there are generally low expectations of health and health services, and a great deal of misinformation. Mental health and cancer are considered taboo subjects and breastfeeding is actively discouraged. There is a widespread belief that cancer is contagious and, if you have one chronic condition then you are safe from any other serious conditions. There are concerns about high suicide and accident rates, particularly in middle-aged men, and reportedly high levels of alcohol use and smoking. Men in particular are unlikely to have any contact with health services unless in crisis.

From the age of twelve onwards, it is common for boys to go out to work with their fathers. Literacy levels tend to be low and there is a strong oral tradition of communication.

2. Gypsies and Travellers in Cumbria

The Cumbria Attitudes Survey 2007 (Cumbria County Council 2007) found that Gypsies and Travellers are the ethnic group most discriminated against in the County.

In the first week of June each year Cumbria hosts the Appleby Horse Fair, one of the largest gatherings of Gypsies and Travellers from all over the country and abroad. Despite this, little is known about the size and distribution of the Travelling community population living on sites and in houses in Cumbria throughout the year, or moving through the county on a regular basis. The Cumbria Gypsy and Traveller Accommodation Assessment (Brown et al 2008) estimated that there were at least 771 local Gypsies and Travellers at the time of the study period; it was acknowledged that this was likely be an under-estimate, particularly amongst the housed population. Although there are only three authorised traveller encampments in Cumbria, it was recognised that the population living in both unauthorised encampments and housing is not accounted for due to the current lack of ethnic coding in national census information. Unfortunately, statistical data is not routinely collected within the NHS about the needs of Gypsies and Travellers or the services they receive. National data about their health and healthcare status is therefore very limited.

As little is known about the health needs, beliefs and service experiences of this group, it was proposed to conduct a Health Needs Assessment (HNA) of the Gypsy and Traveller population in Cumbria.

2.1 Aim and Objectives of the Health Needs Assessment

The overarching aim of this work is:

- To determine appropriate interventions that will have an impact on health outcomes and ultimately reduce the stark inequalities in the health of this minority section of the population of Cumbria.

The objectives are:

- To obtain a comprehensive baseline profile of the health needs of Gypsies and Travellers living in Cumbria.

- To strengthen trust and develop relationships with the Gypsy Traveller population of Cumbria

- To identify strategies and practical initiatives that will address the inequalities in health of this minority section of the population in Cumbria.

2.2 The Project Team

Department of Public Health, NHS Cumbria
O’Neill Consulting
Members of the Cumbria Gypsy Traveller Community
2.3 The stakeholder group

- Members of the Gypsy Traveller community
- Cumbria County Council
- Primary Care Services
- Children’s Services Traveller Education Unit
- Pre-School Learning Alliance
- Cumbria Constabulary
- Local authorities

2.4 Resources

NHS Cumbria Department of Public Health provided £11,000 for this 16 week study. The allocated funding also covered staff costs, room hire, travel and accommodation.

2.5 Definition of concepts

The term “Traveller” will be used in this report to indicate people from any of the following ethnic minority groups: English Gypsy Romany, Irish Travellers, European Roma, Scottish Gypsy Travellers. While acknowledging the differences between these groups, it is recognised that they share many cultural features (Parry et al 2007). The term “Traveller” will also include Show People.

The term will not include New Age Travellers who do not share these traditional features.

2.6 Methodology

In order to engage with the Gypsy Traveller community and gain at least a snapshot picture of the local population, a member of the Gypsy Traveller community was contracted to co-ordinate and manage the data collection and to appoint further members of the local Traveller population to conduct face to face interviews with other local Travellers. A structured interview technique was used to collect data from 103 Travellers across the county of Cumbria.

Two focus groups of purposively sampled Travellers living in Carlisle were conducted to explore their experiences and knowledge and to examine not only what and how people think but why they think that way. Participants were asked to reflect upon a number of questions put forward by the moderator. The following themes were explored:

- Health Experience
- Experiences of using Health Services
- Health Beliefs

Questionnaires were also sent to health professionals in order to explore their involvement and experience (or lack of it) with Gypsy and Traveller patients in Cumbria, and their suggestions for improvement. The questionnaires were forwarded to a sample of GP Practice Managers along with an explanatory letter, requesting that they forward these to all staff members for completion. Staff were offered the opportunity to return the completed questionnaires either electronically, by post or by confidential FAX.
Following meetings with the Acute Trust and the Mental Health Trust, questionnaires and explanatory letters were also distributed to staff at these organisations through their Equality and Diversity Managers. They were given the same range of options for returning the questionnaire as the General Practice staff. 39 health professionals returned questionnaires.

Questionnaires were also sent out to a range of non-health professionals who have regular contact with the Travelling population. 15 non-health professionals returned questionnaires.

Clarification had previously been sought from the Research Governance Manager NHS Cumbria in relation to Local Ethics Committee requirements. Confirmation had been given that, as this work is to inform service improvement, Ethics Committee approval will not be required.

2.7 Analysis

Focus group tape recordings were transcribed verbatim. Following this the transcript was read to ascertain accuracy with the tape recording. Hand written notes were expanded into field notes immediately following the group interviews allowing the researcher to record her own perceptions of the interviewees' actions and responses. Field notes were then typed and coded.

All qualitative data (focus groups, questionnaires) were analysed using elements of grounded theory (Glaser and Strauss 1967) in that relevant categories were identified and open coded using inductive methods to open up the data. Codes were developed from the interpretation of data. The emergent themes drawn from the data were further categorised through constant comparison. Data were analysed by both researchers. This enabled independent repetition of data analysis and therefore increased the reliability of findings (Blaxter 2000).

Quantitative data were analysed using actual numbers of respondents as well as percentages. This technique relates to the relatively small number of respondents, particularly in relation to gender and ethnic grouping within the Traveller population which made it difficult to make generalisations within the wider Traveller population.

2.8 Barriers to Communication

Mistrust of authority figures and organisations by the local Travelling community is seen as a real barrier to effective communication and engagement by both the health and non-health professionals who returned questionnaires. Local Travellers commented during the focus groups that the language used by health professionals can be confusing, frightening and full of meaningless jargon.

“Yes [Doctors] talk in their language all these big words and I will open my mouth and say what do you mean....mine [husband] won’t he’ll just come out and say did you understand that ‘cos I never.” (Female, Focus Group 1)

It was hoped that, by involving Travellers in the design and delivery of structured questions and interviews for the HNA, some of these barriers to effective communication would be minimised.
Other barriers to information and communication identified by participants were:

- Gypsies and Travellers not being included in ethnic coding as part of the national census, resulting in a lack of local and national data.
- Perceptions and low expectations of Travellers by some health professionals.
- Travellers not identifying as Travellers to health professionals.

2.9 Limitations of the data

The findings of this health needs assessment must acknowledge the limitations of the methodology.

The much higher number of Romany Gypsies interviewed than any other ethnic group of Travellers can not necessarily be interpreted as indicating that there is a greater population of Romany in Cumbria than the other groups of Travellers. The researchers did not request the interviewers to collect data from specific quotas of ethnic groups. Therefore the results are likely to be skewed by the interviewers’ knowledge and experience of Traveller contacts in their own area, and their ability to travel across the county.

The same data limitations apply in relation to the place of residence of respondents. The great majority of respondents were resident in Carlisle, but again this may reflect the information available to the interviewers and their awareness of local Travellers.

Further limitations of the data are identified in relation to questions describing individuals and family members identifying as suffering from an illness or mental health issue. As discussed below, it is recognised that there may be some issues relating to the validity of the findings. Some respondents may be related to each other and therefore may share family members with health issues. If so this will give an inflated rate of people reporting such issues.
3. Demographic Profile of Respondents: Gypsies and Travellers

Sample Size: 103

3.1 Gender

49 Male (47 per cent) 54 Female (53 per cent)

Table One: Gender and Age

<table>
<thead>
<tr>
<th>AGE</th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 18</td>
<td>5</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>18 - 24</td>
<td>15</td>
<td>19</td>
<td>34</td>
</tr>
<tr>
<td>25 - 34</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>35 - 44</td>
<td>10</td>
<td>7</td>
<td>17</td>
</tr>
<tr>
<td>45 - 54</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>55-64</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

3.2 Residential area

Figure 1: Area of residence

The majority of Travellers interviewed were resident in the Carlisle area where there is currently one authorised encampment. Although the interviewers adopted a ‘hub-and-spoke’ approach based around the old ‘hawking’ towns of Penrith, Carlisle, Workington and Barrow, the graph does not necessarily reflect the demographic distribution of Travellers in Cumbria. The results are likely to be skewed by the interviewers’ knowledge and experience of Traveller contacts in their own area, and their ability to travel across the county.
Non-health professionals identified that the actual number of Travellers resident in Cumbria remains unknown.

“There are significant numbers of Gypsy/Traveller/Roma people living in Cumbria but we are only aware of the limited numbers who stay on the few sites in the county. We need to use the contacts we have in a smarter way to assess how we can support these communities better” (Cumbria County Council 4)

3.3 Ethnic identity

Figure 2: Ethnicity

```
<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>English Gypsy Romany</td>
<td>78</td>
</tr>
<tr>
<td>Irish Traveller</td>
<td>11</td>
</tr>
<tr>
<td>Show Person</td>
<td>5</td>
</tr>
<tr>
<td>Scottish Traveller</td>
<td>3</td>
</tr>
<tr>
<td>Roma</td>
<td>3</td>
</tr>
<tr>
<td>EGR/ST</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>
```

The majority of Travellers in the sample identified as English Gypsy Romany (EGR), followed by Irish Travellers (IT), Show People (SP), Scottish Travellers (ST) and Roma (R).

3.4 Accommodation

Figure 3: Accommodation Type

```
<table>
<thead>
<tr>
<th>Accommodation Type</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>House/Flat</td>
<td>59</td>
</tr>
<tr>
<td>Caravan/Trailer</td>
<td>43</td>
</tr>
</tbody>
</table>
```
58 per cent of the sample lives in bricks-and-mortar accommodation. The commonly held perception that most Travellers live in caravans or trailers, and the fear of identification expressed by many Travellers, may well contribute to the ‘invisibility’ of the housed Travelling community to services and local authorities.

**Table Two: Accommodation Type and Age**

<table>
<thead>
<tr>
<th>AGE</th>
<th>HOUSE</th>
<th>TRAILER / CARAVAN / MOTORHOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 18</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>18 - 24</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>25 - 34</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td>35 - 44</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>45 - 54</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>55-64</td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>65+</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>

### 3.5 Encampments

**Figure 4: Living on Encampments**

Of the Travellers living on encampments, 78 per cent live on an authorised site and 22 per cent on an unauthorised site (9 Irish Travellers and one Showman).

### 3.6 Family size

Table Three (page 14) illustrates the number of people living in the household of each of the respondents. Of the eight people who lived alone, six were women and two men.
Table Three: Number in Household

<table>
<thead>
<tr>
<th>Number in Household</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives alone</td>
<td>8</td>
</tr>
<tr>
<td>Two people</td>
<td>23</td>
</tr>
<tr>
<td>Three people</td>
<td>24</td>
</tr>
<tr>
<td>Four people</td>
<td>23</td>
</tr>
<tr>
<td>Five people</td>
<td>12</td>
</tr>
<tr>
<td>Six people</td>
<td>8</td>
</tr>
<tr>
<td>Seven people</td>
<td>4</td>
</tr>
<tr>
<td>Eight people</td>
<td>1</td>
</tr>
</tbody>
</table>

The average number of children per respondent was 2.5 with the number ranging from 0 - 8. The most frequently occurring number of children was two per family. This compares with the average number of children per family in the wider UK population which is 1.8.

There were notable differences in family size between the ethnic groups.

English Gypsy Romany respondents reported numbers of children in the family ranging between 0 and 6. 20 per cent of English Gypsy Romany respondents had no children. The average number of children was 2.2.

All the Irish Traveller respondents had children with reported numbers of children in the family ranging between 3 and 8. The average number of children in the Irish Traveller families was 4.6.

88 per cent of respondents stated that they had one or more siblings. Numbers ranged between 0 and 9 with the most frequently occurring number being two.

Again there were large differences in numbers of siblings between English Gypsy Romany respondents and Irish Travellers. The average number of siblings in English Gypsy Romany respondents was 3.1 (Range 0 - 8). The most frequently occurring number was two.

For Irish Travellers the average number of siblings was 6 (range 4 - 9). The most frequently occurring number of siblings was five.

The data therefore indicate that Irish Travellers appear to have considerably larger families than both the English Gypsy Romany group and the wider population.

3.7 Gender roles

The focus group interviews revealed information as to the specific gender roles within the groups. Men were identified as the main family providers.

“.....So they are bread winners, they’re used to bringing money in and can’t bring it in”
"...You've got kids, you've got a wife, you've got to look after yourself, if anything happened to you who's going to look after us"

Focus Group Transcript 1

"Because they've always been fighters. They've always been strong. They've always just got on with it had to get up off their backsides whether they're ill or not .... Nobody is going to put bread and butter in their mouth. Know what I mean? It's as simple as...
 All our kids are strong they've got to be they've got to fight their way through their childhood years."

Women appear to undertake a number of roles within the family.

Women respondents appear to take responsibility for the health of the family.

"Yeah usually in Travellers it is the woman who takes care of all the children and the husbands' well being to the doctors".

Women also appear to be largely responsible for the administrative and organisational tasks.

[Facilitator] "Your husband would ask you to make the appointment at the doctors is that sort of something that happens?"

(all saying yes I do everything)

"Yeah I would"

"I do everything"

[Facilitator] "Would they make an appointment themselves?"

"I would have to make it for him" (all agree)

"...Appointment at the doctors make me an appointment at the dentist I do everything"

"He wouldn't go he wouldn't know how to do it"

"...This is where the woman power comes in...you get the letter you make the appointment and they would go..."
Focus Group Transcript 2

“....they admitted him, so when he phoned me up, said come and get me, I said OK..... so as I'm going up to the ward he's coming down, so I was so pleased he was alright.

... And he walked up to me and said “come on”.

I said “Where we going?”

He went “I'm going home”

I says “are you sure you can go home?”

He said “yes”.

Two hours went by.....phone rang.... “Is your husband with you by any chance?”

I went “yes he's sitting along side me”

“He’s supposed to be in hospital. He walked out but you had to get a blood test 12 hours after the attack to make sure it wasn't a heart attack.”

“He knows, he knows, he's done that before.”

“...... He did go back but as far as he was concerned that attack was finished, the pain had gone, go home so he phoned me ...... He hadn't signed himself out he just walked out.”

3.8 Literacy issues

Parry et al (2004) found that a lack of formal education was common in the Travelling population. They found that while Travellers largely regretted their inability to read and write, they also considered it to be an inevitable consequence of the Travelling way of life.

Jesper et al (2008) found that older Travellers in particular may feel threatened in a hospital setting because many are unable to read and write and may be reluctant to acknowledge this.

Both the focus groups and the Health Professional questionnaires identified problems in relation to illiteracy as a barrier to accessing health services.

“[Facilitator] Do you think that when it comes to Travellers, doctors' surgeries [contacting for an appointment], they should send texts out as well?”

“Mine [husband] can't read. His phone must have 50 messages on. I say
“what's this?” he says ‘how do I know? I can’t read’”

“...many of the women cannot read or write” (Community Midwife 30)

Focus Group Transcript 3

“I asked the people for help and they sent me to a clinic. I’m not the best of readers and writers. He can’t read and write at all and all they wanted to do was fill in a book .... you had to write everything down .... and he couldn’t read it ...... come back in a month when you've filled this book in...... I asked them to sit down with him and explain, no no they never done it like that. I did explain he couldn't read and write. I've been back four times to this same place ...... There's nobody to help you. Waste of service, waste of time.
4. ANALYSIS OF RESULTS

4.1 Registered with a GP

All respondents were asked if they and their families were registered with a doctor.

Figure 5: GP Registration by Ethnicity

86 per cent of respondents stated that they were registered with a GP. This compares with 95.6 per cent of the wider population of Cumbria who are registered with a GP (ONS 2007).

Of the 14 per cent of respondents not registered with a GP, three were English Gypsy Romany (EGR) Travellers and eleven were Irish Travellers (IT); this represents the total sample of Irish Travellers.

Most of the Irish Travellers were living on unauthorised encampments for short periods of time and expressed reluctance to register with a GP as a consequence. Those who had tried had experienced difficulties because of their lack of a recognised permanent address or post code.

“No just stopping here for a few weeks. Tried to register before but they won’t have you without an address.” (M1 IT)

Some Travellers stated that they prefer to use emergency services such as walk-in centres or A & E departments as it’s easier than registering with a GP, despite the fact that this may further compromise continuity of care.

Some EGR Travellers had registered with a GP in another area, despite living locally.

“Yes, Darlington. It was a lot of trouble to get registered even though lived in Workington for six months. Don’t want to register local. Too much trouble” (M56 EGR)
The difficulties for mobile families in accessing services was acknowledged by non health professional respondents:

“There was a concern that ‘transient’ families find it hard to link up with health services” (Carlisle City Council 1)

“Better awareness of access to health services. Bringing those services to them rather than the other way round would I believe be a big step forward” (Eden District Council 6)

4.2 Registered with a Dentist

All respondents were asked if they and their families were registered with a dentist.

Figure 6: Numbers Registered with Dentist

![Registered with Dentist (103 Respondents)](image)

40 per cent of the sample had not registered with a dentist. Further analysis reveals that of the English Gypsy Romany respondents, 67 per cent reported that they were registered with a dentist, compared to none of the Irish Travellers.

This compares with 50 per cent of the general UK population who are registered with a dentist (Medic 8 2009).

“No can’t get one, have tried for years. My teeth are so bad and sore” (M7 EGR)

A minority of those who had registered with a dentist were paying privately.

Although little research has been undertaken into the dental/oral health needs of Gypsies and Travellers, it is likely that the general decline in access to NHS dentists over the past few years will have a greater impact on highly mobile families who are less able to obtain regular check-ups and on-going treatment (Edwards and Watt, 1997).
4.3 Willingness to identify as a Traveller

Respondents were asked whether they were happy to identify themselves as a Traveller when registering with a doctor.

Figure 7: Willingness to Identify as a Traveller to GP Practice

Over half (54 per cent) of the sample stated that they were not willing to identify themselves as a Traveller when registering with a doctor.

When broken down by ethnicity, 51 per cent of English Gypsy Romany respondents reported that they were willing to identify themselves as a Traveller compared to just 18 per cent of Irish Traveller respondents.

Although 86 per cent of the sample was registered with a doctor, it is likely that a considerable proportion of this group have not identified as Travellers to their GPs in Cumbria, despite many positive comments:

“Doctor is good, but I wouldn’t tell him that I was a Traveller.” (F75 EGR)

As identified in a number of other studies regarding the attitudes of Gypsies and Travellers to healthcare services and health professionals (Van Cleemput et al, 2007; Henriques 2001; Honer & Hoppie, 2004), there is a real fear of hostility and/or prejudice from healthcare providers:

“No. Treat you different. Seen it happen over the years. Still happens” (F2 EGR)

Some comments stressed the importance of establishing trust on an individual basis before ‘disclosure’:

“Sometimes - depends on doctor/nurse” (M99 IT)

The responses in relation to being willing to identify themselves as a Traveller were verified by the responses of Health Professionals:

“No-one has ever told me they are a Traveller and I have never written Traveller in a referral or added Traveller to a patient's record”. (24 Practice Receptionist)
“Do not know - patients never class themselves as Travellers/Gypsy/Roma”. (12 Nurse Specialist)

This finding has implications for the ways in which healthcare services are accessed and utilised by Gypsies and Travellers in Cumbria. It also raises the question of whether health professionals in Cumbria would benefit from further awareness-raising regarding the beliefs and culture of Gypsy and Traveller communities.

Further analysis reveals that 55 per cent of respondents living in bricks and mortar accommodation and 53 per cent of those living in a trailer / caravan reported that they would not identify themselves to their GP as a Traveller.

In relation to the area of residence, the following information was obtained.

Of those respondents living in Allerdale, 54 per cent were registered with a GP. 73 per cent reported that they would not identify themselves as a Traveller to their doctor.

Of respondents living in Barrow 70 per cent were registered with a GP. 67 per cent of respondents reported that they would not identify themselves as a Traveller.

Of respondents living in Carlisle, 100 per cent were registered with a doctor. 51 per cent stated that they would not identify themselves as a Traveller.

In South Lakes of the five respondents, none were registered with a GP.

In Eden District there were just five respondents. All were registered with a GP. Just one person (20 per cent) reported that they would not identify themselves as a Traveller.

In Copeland there were three respondents. All were registered with a GP. None of the respondents would identify themselves as a Traveller.

4.4 Understanding GP appointment systems

Respondents were asked whether they understood the doctor’s surgery appointment systems.

Figure 8: Ability to Understand GP Appointment Systems

<table>
<thead>
<tr>
<th>Understand GP Appointment Systems (101 Responders)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>71</td>
</tr>
</tbody>
</table>
30 per cent of respondents stated that they did not understand GP appointment systems. Further examination of the data reveals that, of the EGR respondents, 27 per cent either did not or only partly understood the GP appointment system, compared to 64 per cent of IT respondents who stated they did not understand the GP appointment system.

More mobile Travellers complained of a lack of consistency in booking procedures:

“No it changes all the time” (M48 EGR)

“No seems different at every one” (M1 IT)

“Usually but they all seem different. Receptionists have been funny about living in a caravan. Don’t know what to put on the forms” (F97 IT)

There were also issues about the length of time it takes to be seen by a doctor when travelling from one place to another, and literacy problems with a form/letter-based appointment system:

“Can’t read very much, if they explain properly I can [understand]” (F52 IT)

“No, they are hard to understand. Have to wait weeks to get seen by a doctor” (M66 EGR)

4.5 Interruption of treatment

Respondents were asked whether any treatment that they or their family were having had been interrupted at any time.

Figure 9: Interruption of Treatment

40 per cent of respondents said that they had their treatment interrupted at some time. Of these 32 per cent of EGR respondents reported having treatment interrupted compared to 100 per cent of IT respondents.

The most common reasons given for the interruption of treatment were either because of the need to travel elsewhere to get work (and the consequent difficulty of re-
registering with a new GP), or being evicted/forced to move on:

“Moving around for work or going to help your family” (F2 EGR)

“Having to shift/being evicted” (F97 IT)

Some comments referred to the perceived inability of health services to cope with a mobile lifestyle:

“Mam had to travel back 250 miles when working away” (M60EGR)

“Couldn’t get registered in new town” (M61EGR)

Respondents were also asked if the interruption to their treatment had led to the condition getting worse, and whether they had any problems getting their medication. A number of comments referred to the mental stress caused by treatment being interrupted:

“Yes, worrying about it” (M1IT)

Similar themes emerged concerning the inflexibility of health services:

“Yes. Couldn’t get any more tablets without being at a doctor’s and two doctors I went to said we couldn’t join them without a proper address” (F71IT)

“No, but couldn’t get to use a doctor down the country. I needed a 20 week scan and they wouldn’t do me one, or see a doctor. I was upset by this” (F67EGR)

In one case, interrupted treatment led to potentially dangerous action:

“…..I had a cast on my arm that I took off myself” (M54EGR)

4.6 Sources of health information and support

Respondents were asked whether anyone had been particularly helpful in relation to their health.

There were 93 responses in total.

- 61 (66 per cent) stated that they had found someone (or some organisation) particularly helpful in relation to their health.
- 27 (29 per cent) said that they had not found anyone (or any organisation) particularly helpful in relation to their health.
- 5 (5 per cent) stated that they did not need any help.

Those who responded positively were asked to identify who had been particularly helpful in relation to their health.

- Doctor (36 per cent)
- Traveller Bus/Family Support Worker (26 per cent)
- Health Visitor (13 per cent)
• Hospital (13 per cent)

Others mentioned were: midwife, friends, spouse, counsellor, asthma clinic, physiotherapist, key worker and drop-in centre.

“I have a good doctor, he is very good to me and understands as well as giving good advice” (F31R)

“The Family Support Worker on the Travellers’ bus. She helps me a lot” (F39EGR)

There were several similar comments about the support and advice given by doctors in Cumbria, and about the Traveller bus and family support worker as sources of information and support.

“[Traveller bus Family Support Worker] comes to site once a week. Need her to come more.” (F75EGR)

4.7 Childhood immunisation programmes

Respondents who reported that they had children were asked if their children had received their immunisations.

Figure 10: Childhood Immunisation

42 per cent of respondents said “yes” they have had their children immunised.

42 per cent either had not had their children immunised or had them partly immunised.

16 per cent did not know if their children had been immunised.

Resistance to all vaccinations was identified.

“No, none of them did. I don’t believe in them, they make the kids ill.” (M36 R 7 children)
“No they didn’t get them. I don’t believe in them.” (M7 EGR 4 children)

However, it was noted that Travellers were particularly resistant to the Measles Mumps and Rubella Vaccine (MMR). This resistance largely accounted for those Travellers who reported that they had had their children partly vaccinated. MMR vaccine was linked to the development of autism some years ago. This link has since been discredited, but concern appears to persist within the Traveller community as to its safety.

“Yes but no MMR. I am frightened to give them it, don’t know much about it.” (F30 EGR 2 children)

“Some. I wouldn’t let them have MMR, too dangerous.” (F97 IT 3 children)

“No they didn’t. I wouldn’t let them have them, too many side effects.” (M48 EGR 6 children)

In relation to the uptake of immunisation programmes by ethnic group, none of the Irish Travellers responded that their children had been fully immunised. 6 (55 per cent) reported that their children had been partly immunised and 5 (45 per cent) did not know if their children had been immunised.

“So me I think” (M58 IT 6 children)

In the English Gypsy Romany population 30 reported that their children were fully immunised (49 per cent). 18 reported that their children had been partly immunised (30 per cent) and 6 reported that their children had received no immunisations (10 per cent).

This indicates that there are wide disparities in the uptake of immunisation within the Gypsy Traveller population.

There were also wide disparities between the uptake of childhood immunisation programmes between those Travellers living in bricks and mortar accommodation and those living in caravans or trailers. 57 per cent of those respondents living in bricks and mortar reported that their children had been immunised compared to 20 per cent of those living in caravans / trailers.

When comparing the rates of childhood immunisation uptake in the wider population of Cumbria, the NHS Information Centre (2009) report that for the period 2008/09, 98 per cent of Cumbrian resident children have been vaccinated against diphtheria, tetanus, polio, Hib and pertussis by their second birthday.

91 per cent of Cumbrian children had received MMR vaccine by their second birthday. (NHS Information Centre 2009) This compares to the incomplete rate of immunisation uptake in the Traveller population of Cumbria.

Figure 11 illustrates that the percentage of Traveller children receiving the full immunisation programme (42 per cent) is significantly lower than that of the wider population of Cumbrian children (95 per cent CI 29 to 59 per cent p < 0.05)
The same disparity was identified by Feder et al (1993) in Traveller children in East London who found significant differences in the uptake and completion of childhood immunisation between Traveller children and controls. This study found that the low immunisation rates were due to poor access to services, involuntary mobility, lack of information about community health services as well as the rejection of certain vaccines by Travellers.

4.8 Mental health and wellbeing

Respondents were asked:

“Do you or anyone in your family suffer from nerves or feel low and depressed a lot?”

The term “mental health” was deliberately avoided within the questionnaire. Previous work with Travellers has found that attitudes towards mental health and the terms used to explain them were culturally specific. Researchers found that the term “nerves” was considered acceptable, while the term “mental” was viewed with distrust and was related to madness (MIND 2008).

There were 102 responses to this question.
79 per cent of respondents reported that either they or a family member suffered from depression or “nerves”

Respondents acknowledged that mental health and wellbeing was an issue for Travellers.

“Yes, me and a lot of other women” (F52 IT)

“Yes, a few men including me. Young boy killed himself two weeks ago - relative.” (M58 IT)

Several respondents identified concerns in relation to accommodation as a factor relating to mental health and wellbeing.

“We all worry about money and finding somewhere to stop.” (M1 IT)

“Yes. Live on a bad site gets me down.” (M72SP)

Some respondents reported physical symptoms.

“I have worries, panic attack, lose my breath, shake, feel very bad about it.” (M69 EGR)

The average prevalence of common mental health problems in England is 16.5 per cent of the population (ONS 2003)

Cumbria sits within the North West region which has the highest rate of common mental health problems in England at 20.3 per cent.(ONS 2003)

Focus Group Transcript 4

“So the last one he had is the first time in 15 year it frightened me and I dialled 999 you know as it happened it were the same old thing but to me it was worse. He was oh it was horrible I thought I’d lost him. And they just put it down to stress...... He goes bang down he goes rolling and he’s clutching his chest and he can’t breathe and he’s doing that and the last time he was hyperventilating as well”

It is recognised that there may be some issues relating to the validity of the findings in relation to mental health and wellbeing in this health needs assessment. Some respondents may be related to each other and therefore may share family members with mental health and well being issues. If so this will give an inflated rate of people reporting mental health and wellbeing issues.

However, even given this possibility, the results are striking and indicate that the prevalence of mental health and wellbeing problems within the Travelling community in Cumbria is considerably higher than in both the overall population of the North West Region and in England as a whole.
Further analysis of the data indicates that of those living in bricks and mortar accommodation, 88 per cent report mental health problems compared to 67 per cent of those living in a caravan / trailer.

4.9 General health problems

Respondents were asked:

“Do you or any other members of your family have health problems? For example disability, chronic illness, asthma, diabetes, cancer, blood pressure,’nerves’, depression, heart problems, back problems etc.”

There were 96 responses to this question. 84 per cent of respondents answered ‘yes’, indicating that either the respondent or a family member was not in good health.

This compares to 11 per cent of the overall population of the North West region who report that they are not in good health (ONS 2003), and 23 per cent of the general population who report that they are in fairly good health.

Figure 13: Common health problems

Again there may be some issues relating to the validity and of the findings in relation to this question. Some respondents may be related to each other and therefore may share family members with health problems. If so this will give an inflated rate of people reporting poor health.

In relation to ethnicity, of 75 English Gypsy Romany Travellers responding, 65 reported health problems (87 per cent) while 100 per cent of Irish Travellers reported health problems.

Further examination of the data reveals that of the respondents who lived in bricks and mortar accommodation, 88 per cent reported health problems compared to 79 per cent of those living in a caravan / trailer.
Respondents were asked if they had seen anyone (doctor / hospital etc) regarding their health problems.

81 people responded to this question. Of these 16 had not consulted a health professional (20 per cent).

In relation to mental health issues, those who had sought treatment from a doctor or nurse were asked:

“Did they help, what did they suggest?”

Many respondents referred to treatment with tablets. However there was a general sense that respondents did not find this approach helpful.

“Tablets, tablets and more tablets.” (M5 EGR)

“Yes tablets, but no support or after care given.” (F49 EGR)

“They can’t get me a new site.” (M72SP)

When asked:

“What do you think would have helped?”

There was an overwhelming response to this question relating to the need to talk to someone who understands Traveller culture but is independent in some way.

“It would be nice to talk to someone. You can't talk to other Travellers or it would go right round the camp.” (F38 EGR)

“Talking to the right people, get some right support.” (M48 EGR)

“Talking to someone who is alright with Travellers” (M102 EGR)

4.10 Attendance at Accident and Emergency (A&E) Department

Figure 14: Attendance at A&E Department
There were 101 respondents. 68 (67 per cent) of the sample confirmed that they had attended an A&E department in Cumbria at some time. “Yes lots of times. If I can't get to the doctor's I go to the hospital.” (M10EGR)

Respondents were also asked why they attended A&E. The most common reasons given were:

- taking children (high temperature/fever, asthma, falls, breaks)
- car/motorbike crashes (whiplash, head injury, breaks)
- fights/being attacked (cuts, breaks)
- work/outdoor-related injuries (head/facial/eye injuries, breaks, cuts)
- Heart/breathing problems

4.11 Information and support for Travellers about smoking and alcohol issues

Respondents were asked whether they would like more information and support about smoking and alcohol issues.

From 101 responses, 87 (86 per cent) said that they would welcome more information and support about smoking and alcohol issues.

“Yes Showmen smoke too much” (F11SP)

“All Travellers need support, but they are in denial to the facts” (F67EGR)

There were many comments about smoking, alcohol and drugs being a particular issue for young Travellers:

“Yes. A lot of young people hide the fact that they have a problem with alcohol, smoking and drugs” (F87EGR)

“Drugs is very high within the young Travellers” (F33EGR)

There were also comments about smoking and alcohol being a particular issue for male Travellers, backed up by frank admissions from Traveller men themselves:

“Yes the men really need it” (F52IT)

“Yes. I drink too much but helps with pain in hand” (M58IT)

“Yes I don't understand how you can stop drinking” (M1IT)

There were also some requests for more general information and support:

“More information about all health and doctors” (M100IT)

“Support and understanding on MMR jabs” (F30EGR)
5. Analysis of respondents: Health Professionals

Questionnaires were sent to health professionals across Cumbria in order to explore their involvement and experience (or lack of it) with Gypsy and Traveller patients, as well as their suggestions for improvement. 39 questionnaires were returned.

Figure 15: Professional Area

<table>
<thead>
<tr>
<th>Job Title</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant</td>
<td>1</td>
</tr>
<tr>
<td>GP</td>
<td>12</td>
</tr>
<tr>
<td>Health Visitor</td>
<td>6</td>
</tr>
<tr>
<td>Midwife</td>
<td>2</td>
</tr>
<tr>
<td>Nurse</td>
<td>4</td>
</tr>
<tr>
<td>Receptionist</td>
<td>2</td>
</tr>
<tr>
<td>Unknown</td>
<td>7</td>
</tr>
</tbody>
</table>

20 GP practices returned questionnaires (14 from North Cumbria, 6 from South Cumbria). Questionnaires were also received from North Cumbria Acute Trust staff and Partnership Trust staff. Seven questionnaires (18 per cent of sample) did not state their job title or professional area.

5.1 Contact with Travellers

Respondents were initially asked if they had any contact with Gypsy, Roma or Traveller patients.

Figure 16: Contact with Gypsies and Travellers

<table>
<thead>
<tr>
<th>Contact with Travellers</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td>No</td>
<td>15</td>
</tr>
</tbody>
</table>
Of 36 responses, 17 (47 per cent) reported no known contact with Gypsy, Roma or Traveller patients.

5.2 Identifying patients as Travellers

Respondents were asked how they identified patients as Travellers.

Table Four: Identifying Patients as Travellers

<table>
<thead>
<tr>
<th>Method</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>By Address</td>
<td>18</td>
</tr>
<tr>
<td>History (previous contact)</td>
<td>8</td>
</tr>
<tr>
<td>Self-Identification</td>
<td>8</td>
</tr>
<tr>
<td>Living / come with known Travellers</td>
<td>4</td>
</tr>
<tr>
<td>Physical appearance</td>
<td>4</td>
</tr>
<tr>
<td>Known Family / Relatives</td>
<td>3</td>
</tr>
<tr>
<td>Time of Year</td>
<td>2</td>
</tr>
<tr>
<td>Behaviour</td>
<td>2</td>
</tr>
<tr>
<td>Dress</td>
<td>1</td>
</tr>
<tr>
<td>Accent</td>
<td>1</td>
</tr>
<tr>
<td>Referral</td>
<td>1</td>
</tr>
</tbody>
</table>

Although Figure 5 (page 18) indicates a comparatively high percentage of the Traveller sample registered with a GP (86 per cent), only 53 per cent of the health professional sample reported known contact with Travellers (Figure 16 page 31). Given that 54 per cent of the Traveller sample would not identify themselves as Travellers when registering with a doctor (Figure 7 page 20), it seems reasonable to assume that a considerable number of health professionals will be unaware that they have Traveller patients, a possibility recognised by several health professionals in the sample:

“..........Rarely identify themselves as Travellers” (GP 29)

The leading method of identification is by address i.e. caravan/trailer and/or location on an authorised or unauthorised site, or no fixed address.

“Yes - by address. Not many registered with us” (Nurse 26)

“Various and may well miss some: caravan park address, behaviour, if they say, if they can only make appointments certain months etc” (Consultant 13)

“By address. Register in ‘Devil’s Bridge Lay-by’ on way to and from Appleby Fair in June” (Health Visitor 1)

However, Figure 3 (page 12) shows that over half (58 per cent) of the Traveller sample live in bricks-and-mortar accommodation. The commonly-held perception that most Travellers live in caravans or trailers, combined with the fear of identification expressed by many Travellers, may well contribute to the perceived ‘invisibility’ of housed Travellers to services and to local authorities.
A small minority of health professionals identified Travellers by dress, behaviour and/or appearance.

"Their demeanour is often loud and demand to be seen immediately. Dress code is different, often very smartly dressed in bright colours. Heavily tanned skin." (GP 32)

"Accent, swarthy appearance / suntanned" (GP31)

As has already been seen (Figure 5 page 18), many Travellers are unwilling to identify themselves as Travellers to health professionals because of their fear of discrimination and negative stereotyping:

“No. Treat you different. Seen it happen over the years. Still happens.” (F2 EGR)

5.3 Help to fill in forms
Respondents were asked if they provided Travellers with help to fill in forms.

Table Five: Help Filling in Forms

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
</tr>
<tr>
<td>N/A</td>
<td>1</td>
</tr>
<tr>
<td>Blank</td>
<td>1</td>
</tr>
</tbody>
</table>

The most common response was that help would be given if required or requested.

“..If they request help to do so” (GP Receptionist 17)

“Yes, as many of the women cannot read or write” (Community Midwife 30)

5.4 Non-attendance at appointments
Respondents were asked if there were any specific issues relating to non-attendance at appointments.

Some concerns were expressed about contacting mobile Travellers and continuity of care.

“Do not receive letter, postal service poor on sites” (GP 3)

“Don’t usually let you know if they moved camps and don’t know if they are being seen elsewhere” (Community Midwife 30)

Other issues were raised concerning some Travellers’ expectations of being seen immediately, but generally non-attendance of Travellers was not seen as a major issue.

“I don’t think any worse than the general population!! Can be demanding re wanting appointment now and occasionally DNA if given later appointment."
Sometimes make 1 appointment but whole family wanting seen.” (GP 29)

“No - very good and travel back from other areas for appointments.” (HV 2)

5.5 Health checks and vaccinations

Respondents were asked how Travellers are contacted for health checks, vaccinations etc. 20 responses were received (51 per cent).

6 respondents (30 per cent) stated that Travellers were either not contacted or that they were unable to contact them.

“Unable to contact them as do not usually give address or phone number” (GP 32)

“We do not have an encampment nearby and none apparently registered” (GP 31)

4 respondents (20 per cent) were unsure whether they contacted Travellers for health checks, vaccinations etc. and one respondent (5 per cent) stated that Travellers were only seen for acute problems (HV 1).

9 respondents (45 per cent) stated that Travellers were contacted either by letter, telephone or face-to-face.

“Routine reminder letters are sent according to diary dates on the recall system. Travellers are advised verbally when their next health check will be due (i.e. six months time etc)” (Nurse 39)

“If permanently registered we write to contact address - often no response. Temporary patients not contacted routinely” (GP 29)

This raises the issue of poor literacy levels within the Traveller community as outlined earlier as a barrier to accessing services if Travellers are routinely contacted by letter.

5.6 Immunisation

Respondents were asked if they had any special measures in place to increase the uptake of immunisation by Travellers. There were 20 responses to this question.

- 12 (60 per cent) stated that there were no special measures in place to increase the uptake of immunisation by Travellers.
- 2 (10 per cent) were unsure or didn’t know.
- 4 (20 per cent) stated that they were not involved in immunisation and/or the question was not applicable.
  - 2 (10 per cent) stated that this was either ‘not a problem’ (GP 2) or ‘the same as other patients’ (Nurse 26)

“No, we have no knowledge of previous uptake and they do not present wanting to discuss this usually......but will provide information if required and some do worry about things like mumps or measles for example” (GP 32)
5.7 Confidentiality

Respondents were asked whether they made their (health professionals’) confidentiality obligation clear to Travellers. There were 21 responses to this question. 14 (70 per cent) stated that they do make their confidentiality obligation clear to Travellers.

“Yes - as to all patients” (Nurse Practitioner 11)

“Yes, the same as I do for everyone but they are sometimes not happy to come to a clinic at the same time as someone else from camp” (Community Midwife 30)

8 (30 per cent) stated that they did not directly make their confidentiality obligation clear to Travellers.

“I assume they know it, in the same way as I hope my other patients know it” (GP 2)

5.8 Specific clinical or practical challenges

Respondents were asked if they had any specific clinical or practical challenges when working with Gypsies and Travellers. There were 20 responses to this question.

Table 6: Specific Clinical or Practical Challenges

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuity of care</td>
<td>6</td>
</tr>
<tr>
<td>No specific clinical / practical challenges</td>
<td>6</td>
</tr>
<tr>
<td>Illiteracy</td>
<td>2</td>
</tr>
<tr>
<td>Expect to be seen immediately</td>
<td>2</td>
</tr>
<tr>
<td>Fixed health beliefs</td>
<td>1</td>
</tr>
<tr>
<td>Unclear expectations</td>
<td>1</td>
</tr>
<tr>
<td>High number of family visitors to hospital</td>
<td>1</td>
</tr>
<tr>
<td>Relatives demand hospital overnight stay</td>
<td>1</td>
</tr>
<tr>
<td>Only present with acute problem</td>
<td>1</td>
</tr>
<tr>
<td>Behaviour in GP surgery</td>
<td>1</td>
</tr>
<tr>
<td>Early weaning</td>
<td>1</td>
</tr>
<tr>
<td>Understanding Traveller culture / structures</td>
<td>1</td>
</tr>
</tbody>
</table>

“Sometimes no GP for follow-up, or leaving region so hard to arrange follow-up” (Nurse Practitioner 11)

“....High illiteracy.....can be very demanding. Many will turn up and expect to be seen immediately. For many years we have had an unwritten agreement to do this in order to cut down home visits” (GP 18)

“Knowing certain issues/how community structured etc. helps engagement with this community” (Health Visitor 34)
5.9 Referral by non-health professionals

Respondents were asked whether any non-health professionals had signposted or referred Gypsies and Travellers to them regarding health issues.

There were 20 responses to this question. 15 (75 per cent) confirmed that no non-health professionals had referred Gypsies and Travellers to them regarding health issues; 3 (15 per cent) were unsure; 2 (10 per cent) stated that other Travellers and family members had occasionally approached to discuss concerns.

“The extended family sometimes will approach me to discuss concerns etc” (Health Visitor 34)

“....Used to have good contact from playbus staff, none now” (GP 29)

The non health professionals reported that there was currently no provision for referring Travellers into health services, despite health assessment being a requirement within the Cumbria Joint Agency Unauthorised Encampment Protocol.

“I don’t know who that would be as the health contact on the joint agency protocol for responding to unauthorised encampments is blank for the Eden / Carlisle area.” (Eden District Council 6)

79 per cent of the non health professionals responding felt that a named health professional contact that they could refer Travellers to would be helpful.

‘Yes, but there would need to be several contacts across the county. Such contacts would also be useful for the more effective management of unauthorised encampments. The joint agency group who manage the protocol have had health contacts but the names change regularly and they seem to have little or no knowledge of Traveller issues” (Cumbria Police 15)

5.10 Awareness and use of ethnic Read coding system for Travellers

Read Codes are used to record a patient’s clinical summary information in primary care. They allow some standardisation of the way that information is recorded.

Respondents were asked whether they were aware of the ethnic Read coding system for Travellers and, if so, whether they used it.

There were 22 responses to this question.
15 (68 per cent) were unaware of the ethnic Read coding system for Travellers.

Of the 7 respondents who were aware of the ethnic Read coding system for Travellers, 5 (71 per cent) have used or are using them to identify Travellers.

“Rarely - most Travellers just use ‘white British’” (GP 29)

This would seem to reinforce the finding that the majority of Travellers are not willing to identify as Travellers when registering with a GP.

5.11 Other concerns

Respondents were asked if they had any other concerns about working with Travellers. There were 26 responses to this question.

17 (65 per cent) had no other concerns about working with Travellers. 2 responses perceived a need for patient-held records due to continuity of care issues:

“Lack of continuity of care, would have been easier if they carried a copy of their own medical records. Poor chronic disease management for that reason” (GP 27)
“Yes, if I need to treat them for [a chronic condition] as treatment requires weekly-two weekly visit to the hospital for monitoring plus not all hospitals treat [this condition], so can’t transfer care........A need for patient-held files” (Nurse Specialist 12)

Other issues mentioned were: lack of health professionals’ experience of working with Travellers; child protection; Travellers getting over-the-counter medicines free on prescription; difficulty in getting Travellers to engage with any services; dogs on site when visiting.

A concern raised by non-health professionals related to the difficulty in making contact with the Traveller community directly, and the potential for those agencies already in contact acting as ‘gate keepers’ to the community.

“Building trust and accessing the community directly. I appreciate that there are already groups established and members of the community who already have relationships with the Gypsies/Travellers/Roma community and without these links engaging the community would be near on impossible. That said, I feel there is a danger that whilst this is productive in making links in the first instance I hope it doesn’t lead to ‘gate keeping’ which could further increase inequalities within the community and reduce access to services” (Carlisle City Council 7)

5.12 Potential improvements

Respondents were asked how things could be improved for both the practice and Travellers. Four suggestions/options for improvement were given within the questionnaire:

1. Awareness-raising training.
2. Hand-held health records for Travellers.
3. Production of culturally specific resources and information.
4. Establishing a Primary Care Trust (PCT) contact for specific information.

There were 29 responses to this question.

Figure 19: Potential Improvements
23 respondents selected at least one of the suggestions for improvement.

Hand-held health records were the most popular choice, although some comments noted potential limitations regarding the current use of hand-held child health records.

“Child Health Records used well by families, not so well if attend hospitals” (Health Visitor 3)

“We have [child] hand-held records but they don’t take them to appointments and will have been seen elsewhere but there is no record of this” (Community Midwife 30)

Awareness raising training was the second most popular choice.

“Awareness of problems is the first step” (GP 2)

“...For both clinical and admin staff” (Nurse 39)

“...For Travellers and surgeries” (GP 29)

The third most popular choice was establishing a PCT contact for specific information.

“Specific specialists working directly with this group and to be a contact for other professionals with regard to information etc.” (Health Visitor 34)

“...National list should be available” (GP 29)

11 respondents (48 per cent) chose all four suggestions.

“All of the above. Problems we have are that they move on and don’t always re-register elsewhere so mail returned and sit on our registration database for years with us trying to follow them up!” (Nurse 26)

Other suggestions for improvement involved adapting and improving the flexibility of health services to meet Travellers’ needs, and innovative ways of establishing better links between health professionals and Travellers.

“....Possibly having outreach clinics near or on-site if able....include Travellers in presenting/chatting to health visitors” (Health Visitor 7)

“Generally speaking we have a good relationship with the Travelling community. Twenty years ago we had a high demand for home visits. These have now decreased considerably as we are prepared to see them at short notice” (GP 18)

Lastly, there were some comments about the need for wider cultural change as a pre-requisite to improvement.

“I think that you will find it very difficult to change the culture and advice offered is often met with scorn or disregarded as the mothers always think that they know best” (Community Midwife)

“Less prejudice from health professionals - they [Travellers] are a largely misrepresented group of people” (Nurse 37)
6. Analysis of respondents: non-health professionals

Questionnaires were sent to non-health professionals across Cumbria in order to explore their involvement and experience with Gypsies and Travellers, as well as their suggestions for improvement. 15 questionnaires were returned.

6.1 Organisation/professional area

I. Cumbria Police:
Diversity Officer/Advisor (3)
Police Officer

II. Children's Services - Education:
Headteacher
Senior Teaching Assistant
Nursery Manager
Locality Manager, Specialist Advisory Teaching Service

III. Children's Services - Social Care:
Integrated Services Manager

IV. Cumbria County Council:
Area Support Manager

V. Carlisle City Council:
Community Involvement Officer
Housing Development Officer

VI. Eden District Council:
Principal Environmental Health Officer

VII. Showmen's Guild
E.L.O.

VIII. Willow Grower

The following is a selection of representative responses to each question.

Q1. Do Gypsies/Travellers/Roma People talk to you about their health problems?

Table 7: Talking about Health Problems

<table>
<thead>
<tr>
<th>Response</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>No / Very rarely</td>
<td>4</td>
</tr>
<tr>
<td>Occasionally</td>
<td>6</td>
</tr>
<tr>
<td>Never</td>
<td>5</td>
</tr>
</tbody>
</table>

“Occasionally and when they do it is usually about their children” (Cumbria Police 10)

“Staff report Travellers will talk about health concerns but only when they know and trust the person” (Children's Services 2)

“I think that probably older Travellers are more likely to talk about their [health] issues, but only if they think you are ‘alright’” (Cumbria Police 15)
Q2. If “No” why do you think this is?

“They very rarely engage with statutory agencies......I think Travellers don’t easily talk about their issues if you are not well known to them, or if they think you will be judgmental, or tell people for whom it is none of their business” (Children’s Services 5)

Q3. If “Yes” why do you think this is?

“Frustration because of the difficulties accessing services” (Carlisle City Council 7)

“There was a concern that ‘transient’ families find it hard to link up with health services” (Carlisle City Council 1)

“The people that talk to me are very aware of friends within their community who are very ill (terminally) compared to housed people who get support and help” (Cumbria County Council 4)

Q4. Do you have a specific health professional contact that you can refer or signpost Gypsy/Roma/Traveller people to?

Table 8: Health Professional Contact

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>13</td>
</tr>
</tbody>
</table>

“I don’t know who that would be as the health contact on the joint agency protocol for responding to unauthorised Gypsy and Traveller encampments is blank for the Eden/Carlisle area” (Eden District Council 6)

“Yes - the problem is getting the Travellers to believe they will be treated fairly” (Cumbria County Council 4)

Q5. If “No” would such a contact be useful?

Table 9: Useful Health Professional Contact

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Possibly</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

“Yes a contact would be useful but perhaps a directory of services would also help” (Children’s Services 2)

“Yes, but there would need to be several contacts across the county. Such contacts would also be useful for the more effective management of unauthorised encampments. The joint agency group who manage the protocol have had health contacts but the names change regularly and they seem to have little or no knowledge of Traveller issues” (Cumbria Police 15)
Q6. Do you have any particular concerns about Gypsy/Roma/Traveller health?

“Smoking, alcohol, weight, diet” (Willow Grower 11)

“Yes - the figures around life expectancy and the death of a child in comparison to other sections of society which link to problems accessing and engaging with health services. Access to health services, I believe, is partly due to the lack of authorised sites throughout the country and trust” (Carlisle City Council 7)

Q7. Are there any particular examples of good practice that you are aware of in relation to Gypsy/Roma/Traveller health?

“I do think that setting up a point at Appleby Fair which is the largest Gypsy Traveller event in the country, where they could come for advice and info on health and well-being would be an excellent idea. I am aware that this is something that will hopefully be provided at future Fairs - subject of course to funding” (Eden District Council 6)

“No but I would like to be advised if you come across anything” (Carlisle City Council 7)

Q8. Do you have any particular concerns/challenges in working with Gypsies and Travellers?

“Mistrust of authority figures/organisations” (Cumbria Police 3)

“Building trust and accessing the community directly. I appreciate that there are already groups established and members of the community who already have relationships with the Gypsies/Travellers/Roma community and without these links engaging the community would be near on impossible. That said, I feel there is a danger that whilst this is productive in making links in the first instance I hope it doesn’t lead to ‘gate keeping’ which could further increase inequalities within the community and reduce access to services” (Carlisle City Council 7)

“My concern is the apathy of professionals to make the best use of opportunities” (Cumbria County Council 4)

Q9. Is there anything that could be done to make your work easier or to help overcome the challenges? Awareness training etc.

“Cumbria is desperate for a County strategic lead in Traveller issues. The county is genuinely much better on equality issues generally....but some agencies do need to raise their awareness on Traveller issues” (Cumbria Police 15)

“Awareness training for [police] officers would be useful” (Cumbria Police 8)

“Employing members from the Gypsies/Travellers/Roma community in varying roles throughout the public sector; Gypsies/Travellers/Roma awareness training throughout the public sector; positive media images of the Gypsies/Travellers/Roma people” (Carlisle City Council 7)
“Joint training so the Travellers are also aware of how we live and our beliefs”
(Children’s Services 13)

Q10. How do you think things could be improved for Gypsy/Roma/Traveller people?

“There are significant numbers of Gypsy/Traveller/Roma people living in Cumbria but we are only aware of the limited numbers who stay on the few sites in the county. We need to use the contacts we have in a smarter way to assess how we can support these communities better” (Cumbria County Council 4)

“Better awareness of access to health services. Bringing those services to them rather than the other way round would I believe be a big step forward” (Eden District Council 6)

“Improve environment of permanent sites i.e. not located amongst industry. Showmen should be afforded the same ethnic status as other Travellers. Showmen would tend to delay visiting a GP whilst travelling preferring to wait till they return to base. Delayed diagnosis can be in worst cases fatal. Occasional institutional racism amongst health employees, GPs, nurses etc.” (Showmen’s Guild 9)

“More stopping places” (Willow Grower 11)

“Swifter referrals for pupils who are having difficulty accessing the [school] curriculum (sometimes they have moved on before they can get extra help)” (Children’s Services 12)

“Greater cooperation between G and T communities and local authorities, listen to what they want and don’t make assumptions about their needs” (Cumbria Police 3)

“Increased confidence that issues of discrimination will be dealt with robustly. Better access to health information and advice” (Cumbria Police 8)

“Increased authorised site provision for both transit and permanent pitches” (Carlisle City Council 7)

“A liaison officer that could fill the gap between Travellers and school in a non-threatening way” (Children’s Services 13)

“Site managers could do a great deal more to help Gypsies access services and to facilitate contact between Gypsies and agencies. They are very much the gate keeper and I am not sure for whose benefit!!?” (Cumbria Police 15)
7. Discussion

7.1 Willingness to identify as a Traveller

This health needs assessment has found that more than half of the respondents were not willing to identify themselves as a Traveller when accessing health services. This was largely due to fear of discrimination and humiliation and supports the findings of Van Cleemput et al (2008)

Given that just 53 per cent of the health professionals responding reported known contact with Travellers, this suggests that health professionals are treating Travellers without being aware of their ethnic and cultural identity.

Analysis of the data indicates that 46 per cent of health professional respondents identified Travellers by their address - that is by learning that they live in a caravan or trailer or on an unauthorised site.

The data also identify that more than half of Traveller respondents (58 per cent) live in bricks and mortar accommodation. This suggests that many housed Travellers may be invisible to NHS services.

Only 17 per cent of health professional respondents were aware of the Read code system of identifying Travellers. Of those health professionals who were aware of the Read code system, almost one third did not use it.

A further finding was that Gypsies and Travellers in Cumbria report poorer health than the settled Cumbrian population. Furthermore Traveller respondents living in bricks and mortar accommodation reported higher levels of both general poor health and mental health issues.

These factors suggest that many Travellers are hidden to our health services and therefore are not currently targeted to receive services the way other disadvantaged sections of the population are. This factor can only compound the inequalities in the health of our Cumbrian Traveller population.

This finding has implications for both the ways in which healthcare services are accessed and utilised by Gypsies and Travellers in Cumbria and also for how health services are delivered to our Traveller population. It also raises the question of whether health professionals in Cumbria would benefit from further awareness-raising regarding the beliefs and culture of Gypsy and Traveller communities.

7.2 Immunisation

The study has found significant inequalities between the uptake of childhood immunisation rates by Cumbrian Travellers and that of the settled Cumbrian population. There is a widespread mistrust of immunisation reported within the Traveller community which is particularly related to the MMR vaccine.

Given that there are issues relating to illiteracy within our Traveller population, standard
written information which is provided to enable informed consent for immunisation may be inappropriate for use in this group.

NHS Cumbria has produced culturally specific information for Travellers relating particularly to the MMR vaccine and this is being delivered through the Traveller Family Support Service. However this is on an ad hoc basis and the evidence from this health needs assessment indicates that a much more robust strategy is required to enable herd immunity of these illnesses.

Wide disparities in the uptake of childhood immunisation programmes were noted within the different ethnic groups. Of particular note is the finding that none of the Irish Traveller respondents’ children had been fully immunised.

Further inequalities were identified in the uptake of childhood immunisation programmes in housed Travellers compared to those living in caravans and trailers. The considerably lower number of Travellers’ children living in caravans and trailers who had received immunisation may reflect their difficulty in accessing NHS services. Issues relating to access to services included Travellers reporting being unable to register with a doctor due to lack of a permanent address or a post code. Issues relating to eviction from camp sites were also identified.

There are further implications relating to the introduction of the HPV vaccine as an effective measure in the prevention of cervical cancer. Given that many Traveller girls do not attend secondary school where HPV vaccine is delivered, this indicates the potential for further inequalities in future rates of cervical cancer within the Traveller population. Specific targeted interventions may be required to enable equality of access to HPV vaccine.

Feder et al (1993) following their study of childhood immunisation uptake among Gypsy Travellers in East London, recommend that in order to increase the uptake of such immunisations, systematic outreach should bring immunisation and other preventive services to caravan sites. However, while this strategy may be effective in increasing the uptake by Travellers living on camp sites, it may not address the needs of those living in houses who, although having higher rates of uptake than Travellers living on camp sites, still have uptake rates well below that of the settled population.

Given the issues relating to identifying who and where our Travellers are, particularly Travellers living in bricks and mortar accommodation, strategies need to be developed to encourage all Travellers to access these immunisation programmes.

Further targeting needs to address the specific needs of Irish Travellers to enable and support them to access childhood immunisation programmes.

7.3 Mental health

Self-reported depression, stress and anxiety were strikingly high in the Traveller sample; Travellers living in bricks-and-mortar accommodation reported the highest levels of these conditions. Previous studies have also found a correlation between housed Travellers and poorer health, particularly in relation to long term illness and anxiety.
“Those who rarely travel have the poorest health” (Parry et al, 2004).

Further work (Cemlyn 2000) found that the anxiety levels of housed Travellers were greater than those of non-housed Travellers. This was attributed to isolation from their cultural networks and fears or experiences of neighbourhood hostility.

The prevalence of mental health and wellbeing problems within the Travelling community in Cumbria appears to be considerably higher than in both the overall population of the North West region and in England as a whole.

Further inequalities were identified within the Traveller population with 79 per cent of EGR respondents reporting mental health issues compared to 90 per cent of IT respondents.

The stigma attached to mental health issues within the community may serve as a further barrier to accessing appropriate services. Previous work (Treise and Shepherd 2006) found that the ‘invisibility’ of mental health problems and lack of knowledge and understanding of them within the Traveller community constituted clear barriers to care.

7.4 Ethnicity

There were clear inequalities in health identified in relation to the different ethnic groups.

The English Gypsy Romany respondents had similar rates of being registered with a GP as the settled population. However, none of the Irish Travellers interviewed were registered with a GP. This has considerable implications in relation to access to health services.

Furthermore, EGR respondents were more likely than the settled population to be registered with a dentist, while none of the Irish Travellers were registered.

Overall the general health of respondents was poorer than that of the settled population. The most striking feature was the prevalence of mental health issues in all groups.

7.5 Literacy

Both Travellers and professionals (health and non-health) in this study identified poor literacy levels and a consequent lack of knowledge of health systems as barriers to accessing health services and information. Despite this awareness, healthcare systems are still relatively inflexible and difficult to access for Travellers with low literacy skills.

Complex and variable letter-and-form based appointment systems may well contribute to a reluctance to engage with health services in the first place because of a sense of ‘shame and humiliation’ (Van Cleemput et al, 2008) related to poor literacy skills. Lack of accurate information can lead to a mismatch of expectations between healthcare staff and Travellers that may be perceived by both parties as unwarranted aggression.
or rudeness. PCTs already have health service information routinely translated into ethnic minority languages; production of information in audio form (tape/video/CD) should also be considered.

Some health professionals act as brokers into health services (health visitors, community midwives etc) and are highly valued and trusted by Travellers in Cumbria as a consequence, but this is usually on an ad hoc basis.

Health literacy does not merely refer to the ability to read and write but is the degree to which a person can receive, process and understand health information and services in order to make appropriate health decisions. Travellers in this study referred to difficulty in understanding advice given by health professionals, and the use of jargon as a barrier to accessing effective health care. Interventions, such as the avoidance of jargon, simplified information and illustrations, and encouraging patients’ questions may improve health behaviors in persons with low health literacy.

7.6 General health problems

These findings confirm the evidence from other studies that Gypsies and Travellers have significantly poorer health status and more self-reported symptoms of ill-health than both UK resident English-speaking ethnic minority groups and economically disadvantaged white UK residents.

87 per cent of English Gypsy Romany Travellers interviewed reported general health problems, whereas all the Irish Travellers interviewed reported general health problems.

A combination of poor council housing, fear of identification and discrimination, a feeling of containment and cultural/social isolation may contribute to poorer health for some housed Travellers (Van Cleemput et al 2000). Other self-reported general health problems (in descending order) were: circulatory problems; asthma/breathing difficulties; back problems; diabetes; blood pressure; cancer. Although Travellers interviewed did express concern over their health, there was a general acceptance (particularly amongst older Travellers and Traveller men) that long-term ill health was to be expected as a consequence of leading a Travelling lifestyle. This stoicism may underlie a tendency to denial and delay in presentation for healthcare and/or screening.

7.7 Continuity of care

Lack of continuity of care was highlighted as a major concern by all participants in this study. Interruption of treatment was a frequent cause of self-reported stress and anxiety for a considerable number of Travellers, particularly those forced to move on or those facing eviction.

Practical problems of access and registering with a new GP whilst travelling led to some Travellers having to return great distances just to maintain continuity of treatment; others found it easier to use walk-in centres or Accident & Emergency Departments whilst travelling, thereby further compromising their continuity of care. Suggestions for improvement included: developing more flexible and imaginative ways of taking health services to Travellers; identifying a wide network of GPs who can work well with Travellers; the production of hand-held records for Travellers.
8. Conclusion and recommendations

This Health Needs assessment has reinforced the findings of previous work relating to the health of Travellers in the wider population. However it has also clarified a number of issues and highlighted areas where improvements must be made if we are realistically to reduce the inequalities in the health of Cumbrian Travellers.

The following recommendations are therefore proposed.

1. **Identify appropriate health workers with dedicated time to work with local Travellers**
   Currently some health professionals in Cumbria do occasionally perform this role, but it tends to be on an ad hoc basis. Dedicated/specialist health workers would play an important role in raising awareness amongst Travellers of existing health provision and facilitating equitable access to a range of health services, including mental health services. They would also be a key PCT point of contact for other health professionals.

2. **Health Trainers on each authorised site in Cumbria**
   The introduction of a NVQ qualified Health Trainer on each of the authorised Traveller sites in Cumbria would provide an opportunity to deliver health promotion and improve health literacy for Travellers. Health Trainers would not only link into the work of the Traveller Family Support Service who are engaged with housed Travellers and Travellers living on unauthorised sites, but would also support advocacy work with Travellers in relation to mental health issues.

3. **The introduction of care pathways for Travellers**
   This health needs assessment has identified that those Travellers living on unauthorised sites experience considerably greater difficulties in accessing health services than other members of the Traveller population. It is proposed that the development of multi-agency care pathways for Travellers will improve health outcomes for mobile families. This will require an agreement between the agencies involved outlining agreed roles and responsibilities.

4. **Immunisation programmes**
   The introduction of dedicated immunisation programmes for Travellers. Specific and consistent information should be made available to Travellers which is culturally appropriate. Such programmes should be offered on the authorised Traveller sites and delivered through the appointed dedicated health professional. In relation to Travellers residing on unauthorised sites and where Travellers are not registered with a GP, a specific immunisation protocol should be developed in order to offer immunisation for Travellers on site.

5. **Implement mandatory cultural awareness training for all PCT staff that may interact or have contact with Travellers or other vulnerable groups**
   This should be part of existing Equality and Diversity programmes and Travellers should be involved in the design and delivery of courses. This will enable the provision of more culturally sensitive services for Travellers. Any such training programme should be evaluated for its effectiveness at changing attitudes.
and influencing service delivery. Such cultural awareness raising programmes may empower Travellers to acknowledge their ethnicity more readily when accessing services.

6. **Ethnic monitoring**
   In order to realistically address the inequalities in the health of our Traveller population there needs to be a much greater knowledge of who they are and where they reside. Primary care staff should be made aware of the Read codes for the different groups of Gypsy Travellers, and should be required to record their ethnicity on patient records.

7. **Develop patient-held records for adult Travellers**
   There is strong support for this initiative from local health professionals and Travellers as a way of improving continuity of care. Cumbria PCT should work closely with the Department of Health and other PCTs to develop a national template. The use of electronic hand-held records should be explored as a second stage of development. This should have a considerable impact in reducing the number of Travellers who have their treatment interrupted when travelling.

8. **Support the development of a county/regional network of good practice in primary care**
   This study encountered several examples of individual surgeries and health professionals that were known and valued by Travellers in Cumbria as ‘culturally safe’ (Van Cleemput et al 2007) and flexible to their needs. All health services in Cumbria should work towards this goal, but there may be some short-term benefit in sharing good practice through the formation of ‘hubs of expertise’. This should be a regional network in order that mobile Travellers may be signposted to ‘culturally safe’ GP surgeries in other areas.
REFERENCES


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MIND Bristol (2008) Do Gypsies, Travellers and Show People get the support they need with stress depression and nerves? Findings from a research project by Bristol MIND. Presentation to the West of England Gypsy, Traveller and Show People Forum, February 2008, Bristol Mind


Van Cleemput P (2000) Health care needs of Travellers. Archives of Disease in Childhood 82, 32-37

Introduction to participants:
We are working with Ian Twiselton and Fiona Huntington from NHS Cumbria, to ask Gypsies, Travellers and Roma people living in the area about what type of health problems they have and the type of services which can provide them with support. Richard O’Neill is co-ordinating this work. He will be working with local Travellers to find out about Travellers’ health needs. Richard is a Traveller who is very experienced in this kind of work.

We would like your help in answering the following questions, which will take about half an hour. We would like to take your post code (if you agree).

All the information we collect is anonymous so you can speak freely.

We hope that this survey will help NHS Cumbria learn about the health needs of Gypsies, Travellers and Roma people living in the area.

Are you happy to answer some questions about you and your family's health?

Signature of Data Collector to indicate the Traveller has given verbal consent.

Area of Cumbria:

Code interview: (interviewer initials)

Date of interview:

Place of interview:

Person(s) interviewed:

   Man   Woman

Age:

Type of accommodation:

Caravan/House/Bungalow/Other (please specify)

Authorised Encampment

Unauthorised Encampment
COMMUNITY MEMBER QUESTIONNAIRE

1. How would describe yourself?

   English Gypsy/Romany          Irish Traveller
   New Traveller                 Roma            Show Person
   Other (specify)

2. Are you and your family registered with a doctor?
   (If yes ask which area GP practice is in. If no ask reasons why not. Were there any particular difficulties? were they put off by friends or relatives?)

3. Are you and your family registered with a dentist?
   (If ‘yes’ ask which area dental practice is in. If ‘no’ ask reasons why not? Were there any particular difficulties? Were they put off by friends or relatives?)

4. How many people live with you? (take numbers)

   Husband/wife         Parents
   Children (take ages)
   Other

5. How many brothers and sisters do you have?

6. Do they live nearby?

7. How many children do you have?

8. Have they had their vaccinations

9. Do you or any other members of your family have health problems? For example disability, chronic illness, asthma, diabetes, cancer, blood pressure, ‘nerves’, depression, heart problems, back problems etc.
10. If you answered “yes”, please give details

11. Have you seen anyone about your health problems? Doctor / hospital. (Record which)

12. When you register with a doctor are you happy to identify yourself as a Traveller?

13. Do you understand the Doctor’s surgery appointment systems?

14. Are you receiving any specialist/hospital treatment?

15. If you answered “yes” to the above question do you have any difficulties with transport to reach your appointments

16. Are you on any regular medication / tablets (please state)

17. Has any treatment you or your family had been interrupted?

18. If you answered “yes” to the above question please specify the reasons why you didn’t continue treatment. (E.g. having to shift / being evicted / problems with registering / having to move out of the area for work / seasonal traveling / Other)

19. If you answered “yes” has this led to the condition getting worse?

20. Have you ever had any problems getting your medication (please state)
21. In relation to your health has anyone been particularly helpful?

22. If you answered yes, please specify
   Health Visitor   Traveller Education Service   Other

23. How did you hear about them?

24. Do you know about any well woman / well man clinics at your doctors?

25. If “yes” do you attend them?

26. Do you or anyone in your family suffer from nerves or feel low and depressed a lot?

27. Have they/you seen your doctor or nurse about it?

28. Did they help / what did they suggest?

29. What do you think would help?

   **Probe:** e.g. - living nearer family; not being in a house, talking to someone; etc.

30. Have you ever had to attend the A&E department in Cumbria?

31. If yes are you able to say what for?
32. Do you think that Travellers would like more information about support for smoking / alcohol issues?

Thank them for their help.

Ask if they will be willing to take part in a focus group? If so get contact numbers.
Dear Colleague

Gypsies and Travellers in Cumbria: Health Needs Assessment

As you may well be aware, evidence indicates that Gypsies and Travellers have significantly poorer health status and more self-reported symptoms of ill health than both other UK resident English-speaking ethnic minority groups and economically disadvantaged white UK residents.

Local consultation with the Gypsy and Travelling communities in Cumbria has revealed that there are generally low expectations of health and health services and a great deal of misinformation.

Public Health has managed to secure a small amount of funding to conduct a health needs assessment with Gypsies and Travellers in Cumbria. Local Travellers are being commissioned to carry out face-to-face interviews with other local Travellers across the County.

As part of this process, we would also like to get feedback and suggestions from healthcare professionals about their involvement and experience (or lack of it) with Gypsies and Travellers in Cumbria. We are hoping to collect data from the following members of staff:

- Practice Nurses
- Health Visitors
- Midwives
- Receptionists
- GPs
- Allied Health Professionals

We would be very grateful, therefore, if you could distribute the questionnaire amongst your staff.

We are sending the questionnaire out both electronically and by post to enable staff to complete it either electronically, by fax or by hand.

Please would you request that the questionnaires are returned by Friday 19th June to:

Fiona Huntington
Health Improvement Specialist
Department of Public Health
We are proposing to hold a dissemination seminar on completion of the Health Needs Assessment; those who have returned questionnaires will be given preferential invitation to the event. Thank you for your time.

Yours Sincerely

Jane Muller
Associate Director of Public Health (North Cumbria)

Gypsy Traveller Health Needs Assessment: Health Professionals Questionnaire

1. Do you have any contact with Gypsy, Roma or Traveller patients? If ‘YES’ please go to Question 1a. If ‘NO’ please go to question 2a.

1a. How do you identify them as Travellers? E.g. address, identify themselves as Travellers, known to be Traveller from previous contact, come with known Travellers, other (please state).

1b. Do you provide Travellers with help to fill in forms?

1c. Are there any specific issues relating to non-attendance of appointments?

1d. How are Travellers contacted for health checks, vaccinations etc?

1e. Do you have any special measures in place to increase the uptake of immunisation by Travellers?

1f. Do you have any special measures in place to increase the uptake of health checks / screening programmes for Travellers?

1g. Do you make it clear to Travellers about your confidentiality obligation to them?
1h. Are there any specific clinical or practical challenges you have when working with Gypsies and Travellers.

1j. Do you have any non-health professionals who sign-post or refer Gypsies and Travellers to you regarding health issues?

1k. Are you aware of the ethnic READ coding system for Gypsy / Roma / Travellers?

1l. If “yes” do you use these codes to identify Gypsy / Roma / Travellers?

NOW PLEASE GO TO QUESTION 3.

2a. Have you ever had any contact with Travellers?

2b. If “No” how do you know you have never had any contact with Travellers?

2c. Are there any concerns you have about working with Travellers?

NOW PLEASE GO TO QUESTION 3.

3a. How do you think things could be improved for both the practice and Gypsies / Travellers?
   E.g.
   • Awareness raising training
   • Hand held health records for Travellers
   • Culturally specific resources / information
   • PCT contact for specific information

Many thanks for completing this questionnaire. Please return it either electronically or by post to:

Fiona Huntington
Health Improvement Specialist
Department of Public Health
4 Wavell Drive
Rosehill
Carlisle
CA1 2SE

E-mail: Fiona.huntington@cumbriapct.nhs.uk.
APPENDIX THREE
NHS Cumbria Gypsy / Roma / Traveller Health Needs Assessment
Professionals (non health) Questionnaire

Doctors, priests and other religious leaders
Environmental Health
Children’s Services Traveller Education Unit
Police

1. Do Gypsies / Travellers / Roma people talk to you about their health problems and concerns?

2. If “no” why do you think this is?

3. If “yes” why do you think this is?

4. Do you have a specific health professional contact who you can refer or signpost Gypsy / Roma / Traveller people to?

5. If “no” would such a contact be useful?

6. Do you have any particular concerns about Gypsy / Roma / traveller health?

7. Are there any particular examples of good practice that you are aware of in relation to Gypsy / Roma / Traveller health?

8. Do you have any particular concerns / challenges to working with Gypsies and Travellers?

9. Is there anything that could be done to make your work easier or to help overcome the challenges? Awareness training etc.

10. How do you think things could be improved for Gypsy / Roma / Traveller people?
APPENDIX FOUR
NHS Cumbria Gypsy / Roma / Traveller Health Needs Assessment
Focus Group Questionnaire

Topic Guide Focus Groups

- Health Experience
- Health service experience
- Health beliefs.

1. Anybody willing to share any problems they’ve had or are having with their health?

2. How did you deal with it?

3. Did you get any help from anybody?

4. What are your experiences of using health services?

5. Any good experiences?

6. Any bad experiences?

7. How did that make you feel?

8. How could it have been better?

9. How could health services better help Travellers?

10. Have you got children?

11. What do you do if your child becomes ill?

12. How do you feel about having your children vaccinated against things like measles, mumps, and whooping cough?

13. Women: How do you feel about cervical screening / mammograms?
    Men: How do you feel about going for health checks: blood pressure, diabetes etc?

14. What are your main health worries? What are you most afraid of?

15. What would most improve the health of Travellers?

16. Who in your family takes responsibility for the family’s health generally?

17. Do you / have you used your GP practice for maternity care?

18. Do you use medical services for family planning?