

HEALTH WITHIN THE LEEDS ROMA COMMUNITY: FINAL REPORT

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Executive Summary

Introduction

This report illustrates the findings from a piece of health-related research carried out within the Roma community in Leeds in 2012. The research aimed to explore Roma community member's health status and associated health needs. Based upon data gathered from questionnaires and focus groups with Roma community members and interview data from health professionals working with them, this report presents evidence from the data gathered. The findings reported here relate to the migrant population of Roma resident within the UK, not the indigenous Gypsy and Traveller population of the UK. UK and Irish Travellers, despite sharing common experiences to the Roma in terms of discrimination and exclusion, are a distinct community and are not of Roma origin and thus are not the focus of this report.

Background

Existing evidence shows that many Roma communities have received little attention in relation to their health requirements despite a large evidence base that illustrates how the Roma community suffer from poorer health and unhealthier living conditions when compared to majority populations (Masseria, et al. 2010) and that their poor health can be closely linked to the wider social determinants of health (Foldes and Covaci 2012). More evidence is needed to understand the health needs, support requirements and barriers faced by the Roma community to begin to inform strategies and ways of working as mechanisms to tackle health inequalities. This research will contribute to the local evidence base by providing insight into the health of the Leeds Roma community.

Research aims and objectives

The overall aim of this research was to identify the health status/needs of Roma communities within Leeds as a mechanism to begin to understand how to work towards reducing health inequalities and how to improve access to services. This research was commissioned by NHS Leeds in 2012. The key objectives were to

- Involve Roma communities in gathering local intelligence
- Build the capacity of members of the Roma community to undertake research work
- To identify the local barriers in accessing primary and secondary health care services from the perspective of Roma community members
- To identify wider determinants that have an impact on health and wellbeing within the Roma community (for example poverty, employment, education and housing)
- To make recommendations and suggest interventions and strategies to address the gaps identified.

Key messages from the research

- Involving Roma communities in gathering local intelligence was successful with access easier in the areas of Leeds where more long-standing networks and higher levels of trust existed. Involving community leaders within this project led to increased trust which may support opportunities for further research in the future.
- The research has been able to identify language as a key barrier in relation to accessing health care and understanding health messages.
- Participants understandings of the health system were hindered by their different experiences within their countries of origin hence frustration was expressed when no examinations were undertaken during consultations as well as in instances where prescriptions were not discharged. Thus, some participants expressed a lack of confidence within UK health service provision.
- The research highlighted several wider determinants of health as key concerns within the Leeds Roma community including housing, employment opportunities, education and money. At the time that the research was conducted, national welfare reform was taking place which reflected in participant concerns related to on-going financial support.
- Lack of understanding about health care provision, feeling disempowered when ill, language barriers and general concerns about work and money were highlighted as key causes of stress by those who participated within the research.

Overall summary of research findings

- *Community Issues:*
When asked about the community problems in their local area, respondents highlighted isolation, street cleanliness, crime and unemployment as the key issues.
- *Experiences of discrimination:*
47.7% of respondents reported that they did not feel that they had faced discrimination or prejudice whilst being in the UK because they were Roma. However, 13.6% reported that they had faced prejudice all of the time.
- *Health Services:*
 1. The majority of respondents (91.4%) were registered with a doctor, although only just over a half (55.7%) were registered with a dentist.

2. The most popular source of help for medical advice was the GP (80% of respondents), followed by friends and family (37.1%) and then Accident and Emergency (12.9%).
 3. Respondents from cohort 1 also showed good levels of awareness of childhood immunisation programme (88.6% were aware) and there were also high levels of awareness of pregnancy/childhood screening programmes (77.3% for new born screening and 59.1% for anti-natal screening). However, there was less awareness of NHS health checks (18.2%).
 4. Almost half of the respondents described the service that they received from their GP as good (31.4%) or excellent (10%)
 5. More than half of the respondents (57.1%) who had used hospital services within the last year reported the services as good. However, 12.2% rated them as poor and 17.1% felt ok/indifferent in relation to hospital services.
 6. Large numbers of respondents reported language barriers as a problem when using health services (77.1% saying language was an issue always/most of the time). Cohort 1 commonly suggested provision of language support would make a difference to them.
- *Experiences of stress:*
The majority of respondents (91.4%) reported feeling high levels of stress during the past year, with the most common cause of this being money problems (64.3% of the sample).
 - *Health-Related Behaviours:*
 1. 67.1% of questionnaire respondents were current smokers.
 2. Almost half (51.4%) of the respondents reported that they consumed alcohol 'monthly or less', and a further 40% stated that they never drank alcohol.
 3. Over half of respondents (54.3%) reported it 'very easy' to access fruit and vegetables but only 1.4% consumed the recommended daily allowance of 5 or more portions per day.
 4. Over a third (34.3%) of respondents were physically active for 30 minutes 5 or more times per week.

Several themes emerged from the data indicating that Roma community members require support in a number of areas including;

- Language support (in a variety of forms, including interpreters);
- Understanding rights and entitlements (related to housing and welfare benefit provision);
- Work and money advice;
- Understanding how health services work, as well as appropriate points of access.

The qualitative data also showed that there are varied experiences of discrimination within the Roma Community, as well as some perceptions of disempowerment related to

language barriers and expectations of services. Health messages were also viewed with some level of suspicion by those who participated in the research.

When asked what health services could do to help, the participants again highlighted the need for language support such as information in their own language and the use of pictures as well as more workers from the Roma Community.

Recommendations

Given the issues reported here in this small-scale piece of data collection attention needs to be paid to;

- The language barriers that exist and the need for associated language services, levels of literacy and the development of appropriate communication tools. In particular language support should be given attention in relation to health service provision.
- The need for education about health care provision, points of access and healthy behaviours. Interventions should focus upon increasing Roma access and understanding of the nature of services and treatment.
- Employment options and related support for Roma community members should be considered as mechanisms of support and ways of tackling the wider determinants of health.
- Localised support (for example from third sector organisations who are able to deliver outreach) would be a useful tool in addressing some of the other needs identified within the research e.g. housing and welfare benefit advice
- There is also now an increasing requirement to consider the health needs of the Roma community within the broader requirement of the health needs of other migrant Communities, reflecting the population changes in Leeds.

1. Introduction

The term 'Roma' is used by the European Commission to refer to a number of different groups. "The term "Roma" is used here, as well as by a number of international organisations and representatives of Roma groups in Europe, to refer to a number of different groups (such as Roma, Sinti, Kale, Gypsies, Romanichels, Boyash, Ashkali, Egyptians, Yenish, Dom, Lom) and also includes Travellers, without denying the specificities and varieties of lifestyles and situations of these groups." (European Commission 2012). For the purposes of this report the findings relate to the migrant population of Roma resident in the UK, not the indigenous Gypsy and Traveller population of the UK. UK and Irish Travellers, despite sharing common experiences to the Roma in terms of discrimination and exclusion, are a distinct community and are not of Roma origin. It is difficult to say how many Roma are resident in Leeds. Based on estimates from the RICE project (linking schools and Roma communities in Leeds with schools and Roma communities in Brno, Czech Republic) the population of Gypsy, Roma and Travellers resident in Leeds is likely to be somewhere around 5000.

Roma have been migrating to the UK for years but the number of migrants has increased, first through those seeking asylum, and latterly through the enlargement of the EU in 2004 and 2007. Despite this, there is a lack of data in relation to numbers of Roma resident in the UK and in Leeds. While for the first time in 2011 the UK Census included Gypsy/Traveller as a top level ethnicity category it did not include Roma as a choice. Population estimates for the UK vary widely however a report by Brown et al (2013) estimated a population size of at least 197,705 Roma living in the UK as of 2012. The data from that report indicates that the population of migrant Roma is predominantly urban and located within existing multi-ethnic areas with significant population in several areas of the UK including Yorkshire and the Humber. The report estimates that there are 25,451 Roma in Yorkshire and the Humber. A Social Audit in 2006 in Leeds identified significant number of Roma settled in the Harehills area of Leeds (Travellers Health Partnership 2006). Furthermore, there are also concentrated numbers of Roma families living in Armley and Beeston. Generally, families that have chosen to come to Leeds have mostly come from Slovakia, the Czech Republic and Poland. Hence, the need for research in this area resulting in this piece of work being commissioned by NHS Leeds in 2012 to identify the health status/needs of Roma communities in Leeds.

Key drivers for undertaking this work were:

- The 2010 DH white paper Equity and Excellence: Liberating the NHS highlighted the importance of ensuring the NHS provides fair and equitable healthcare to the whole population.
- 2006 Social Audit in Leeds highlighted critical issues related to health and wellbeing, such as high reported incidences of long term conditions.
- Anecdotal local evidence from the Roma Partnership Group and Inner East Multi-agency Group suggested that local Roma communities were experiencing significant barriers to accessing health and social care services.

- There is a lack of formal information pertaining to the health needs of the Leeds Roma population, with Gypsy, Traveller and Roma populations identified as an information gap in the 2012 Joint Strategic Needs Assessment for Leeds.
- The difference in life expectancy of the Roma populations compared to the national average illustrate the existence of health inequalities.
- The Public Health Outcomes Framework under domain four states that preventing premature mortality, reducing the numbers of people living with preventable ill health and numbers of premature deaths, while reducing the gap between communities should be prioritised.

2 How the research was done

Research objectives

The key objectives of the research were to

- Involve Roma communities in gathering local intelligence
- Build the capacity of members of the Roma community to undertake research work
- To identify the local barriers in accessing primary and secondary health care services from the perspective of Roma community members
- To identify wider determinants that have an impact on health and wellbeing within the Roma community (for example poverty, employment, education and housing)
- To make recommendations and suggest interventions and strategies to address the gaps identified.

Overview of the research process

This research was conducted by a Roma bilingual advocate and two Roma volunteers who worked on the study and undertook the surveys. The research was conducted in 2012 and used a mixed method approach including data from focus groups with Roma community members, interviews with local health professionals and questionnaires again with Roma community members. Surveys were delivered in Slovak, Czech and Romani.

The project was delivered in three phases:

1. In the first phase, 44 surveys were completed as well as 3 topic based focus groups by May 2012, with the majority of the participants being from the Harehills area of Leeds. Focus groups were topic based with the schedules exploring a range of issues including:
 - Experiences of using services such GPs, Doctors and Hospitals;
 - Healthy lifestyles: including diet and exercise, what people felt they were doing well, and where they felt they required more support;
 - Experiences of work and income, stress related to these areas as well as perceptions about the support people required to improve their work and health.
2. A second wave of surveys was undertaken to try and obtain information about the Armley and Beeston communities. A total of 26 surveys were completed and a further 2 location-based focus groups were undertaken, 1 in Armley and 1 in Beeston as a mechanism to capture the views of members of the Roma community living within these areas.
3. Phase three involved interviewing professionals who come into contact with the Roma community through the course of their work. A total of 5 interviews were carried out. Efforts were made to try and get a cross cutting field of people who had both 'hands-on' experience and more strategic experience of working with the community. Within these 5 interviews, there was representation from GP services, a Roma community activist working within migrant services, people employed within

council services holding a specific remit to work with Roma, Gypsy and Traveller communities.

Focus Group Participation

Table 2.1 – Overview of focus group participants

| Focus group discussion | Participant information |
|---------------------------------------|----------------------------------|
| Harehills: GPs, Doctors and Hospitals | 7 male and 7 female participants |
| Harehills: Healthy Lifestyles | 2 male and 4 female participants |
| Harehills: Work and Income | 5 male and 5 female participants |
| Armley | 8 male and 1 female participants |
| Beeston | 2 male and 2 female participants |

A total of 43 participants contributed to the focus group discussions. No further demographic information about the focus group participants is available.

Questionnaire respondents

A total of 70 respondents completed the questionnaire; 44 respondents completed the questionnaire in Phase 1 (Cohort 1) and 26 in Phase 2 (Cohort 2).

Data Analysis

Analysis of the resulting data was undertaken by the Public Health Intelligence Team using thematic analysis for the qualitative data collected, and descriptive statistical analysis for the questionnaire data.

Limitations of the research

Initially it was intended to gather 100 surveys, however a total of 70 responses were garnered limiting the statistical analysis of the data gathered. Factors that may have affected responses to the survey included;

- The initial survey took over an hour to complete, hence was time-consuming for all involved and may have thus limited responses.
- Community access may have been an issue. Access to communities in Armley and Beeston was difficult. These communities are smaller and there is generally less engagement with support services in these areas. Unlike Harehills where a level of community trust exists, engagement with the Armley and Beeston communities is still in its relative infancy.
- It is not possible to ascertain whether any of the focus group participants also completed the questionnaires. This coupled with small numbers of respondents to the survey means care must be taken when interpreting results as similar findings

from the survey and focus groups may be due to responses by the same individuals.

- The small number of respondents to the survey means that it is not possible to express statistical significance in relation to the quantitative data gathered.
- Translation of the focus group schedules poses a small risk of losing some of the nuances within the conversations recorded.
- The Roma Community are diverse in terms of areas where they have moved from, languages spoken and views of each other hence the different experiences, expectations and understandings of UK systems reported within this research may not be generalizable to other local Roma populations.

Despite these limitations, the data gathered still illustrates some powerful and consistent messages, which are similarly evident within other national and international studies of the Roma community.

3. The research findings

Summary of research findings: results from the questionnaire:

- *Community Issues:*
When asked about the community problems in their local area, respondents highlighted isolation, street cleanliness, crime and unemployment as the key issues.
- *Experiences of discrimination:*
47.7% of respondents reported that they did not feel that they had faced discrimination or prejudice whilst being in the UK because they were Roma. However, 13.6% reported that they had faced prejudice all of the time.
- *Health Services:*
 1. The majority of respondents (91.4%) were registered with a doctor, although only just over a half (55.7%) were registered with a dentist.
 2. The most popular source of help for medical advice was the GP (80% of respondents), followed by friends and family (37.1%) and then Accident and Emergency (12.9%).
 3. Respondents from cohort 1 also showed good levels of awareness of childhood immunisation programme (88.6% were aware) and there were also high levels of awareness of pregnancy/childhood screening programmes (77.3% for new born screening and 59.1% for anti-natal screening). However, there was less awareness of NHS health checks (18.2%).
 4. Almost half of the respondents described the service that they received from their GP as good (31.4%) or excellent (10%).
 5. More than half of the respondents (57.1%) who had used hospital services within the last year reported the services as good. However, 12.2% rated them as poor and 17.1% felt ok/indifferent in relation to hospital services.
 6. Large numbers of respondents reported language barriers as a problem when using health services (77.1% saying language was an issue always/most of the time). When asked about what would make the biggest difference, cohort 1 answers common related to the provision of language support.
- *Experiences of stress:*
The majority of respondents (91.4%) reported feeling high levels of stress during the past year, with the most common cause of this being money problems (64.3% of the sample).

- *Health-Related Behaviours:*

1. 67.1% of questionnaire respondents were current smokers.
2. Almost half (51.4%) of the respondents reported that they consumed alcohol 'monthly or less', and a further 40% stated that they never drank alcohol.
3. Over half of respondents (54.3%) reported it 'very easy' to access fruit and vegetables but only 1.4% consumed the recommended daily allowance of 5 or more portions per day.
4. Over a third (34.3%) of respondents were physically active for 30 minutes 5 or more times per week.

Summary of research findings: results from the focus groups and interviews:

Several themes emerged from the data indicating that Roma community members require support in a number of areas including;

- Language support (in a variety of forms, including interpreters)
- Understanding rights and entitlements (related to housing and welfare benefit provision)
- Work and money advice
- Understanding how health services work, as well as appropriate points of access.

The qualitative data also showed that there are varied experiences of discrimination within the Roma Community, as well as some perceptions of disempowerment related to language barriers and expectations of services. Health messages were also viewed with some level of suspicion by those who participated in the research.

When asked what health services could do to help, the participants again highlighted the need for language support such as information in their own language and the use of pictures as well as more workers from the Roma Community.

Findings from the questionnaire

A total of 70 respondents completed the questionnaire; 44 respondents completed the questionnaire in Phase 1 (Cohort 1) and 26 in Phase 2 (Cohort 2).

Overall, 67.1% of respondents were females and 58.6% aged between 31 and 50 years. 82.9% described their ethnic background as Roma and 68.6% their citizenship status as Migrant worker EU. Over half of respondents resided in LS8 (31.4%) or LS13 (20%). 87.1% of the sample did not classify themselves as a carer. For a full breakdown of sample demographics please see Table 3.1

Table 3.1. Questionnaire respondent demographics

| | | Frequency (%) |
|--------------------|---|---------------|
| Sex | <i>Female</i> | 47 (67.1) |
| | <i>Male</i> | 19 (27.1) |
| | <i>Missing data</i> | 4 (5.7) |
| Age | <i>18-30</i> | 18 (25.7) |
| | <i>31-50</i> | 41 (58.6) |
| | <i>51-64</i> | 8 (11.4) |
| | <i>65+</i> | 2 (2.9) |
| | <i>Missing data</i> | 1 (1.4) |
| Ethnicity | <i>Roma</i> | 58 (82.9) |
| | <i>Vlacho Roma</i> | 7 (10) |
| | <i>Other</i> | 3 (4.3) |
| | <i>Missing data</i> | 2 (2.9) |
| Citizenship status | <i>British Citizen</i> | 1 (1.4) |
| | <i>Migrant worker EU</i> | 48 (68.6) |
| | <i>Migrant worker A2</i> | 1 (1.4) |
| | <i>Non EU Migrant worker</i> | 1 (1.4) |
| | <i>Family Migrant – Permanent residency</i> | 18 (25.7) |
| | <i>Missing data</i> | 1 (1.4) |
| Postcode area | <i>LS8</i> | 22 (31.4) |
| | <i>LS9</i> | 11 (15.7) |
| | <i>LS11</i> | 6 (8.6) |
| | <i>LS12</i> | 8 (11.4) |
| | <i>LS13</i> | 14 (20) |
| | <i>LS18</i> | 2 (2.9) |
| | <i>Missing data</i> | 7 (10) |
| Carer | <i>No</i> | 61 (87.1) |
| | <i>Yes</i> | 6 (8.6) |
| | <i>Missing data</i> | 3 (4.3) |

Long term conditions and disability

30% of respondents stated that either themselves, or a family member living in the same household, had a longstanding illness or disability. Of these respondents, 38.1% had someone in the household registered as disabled.

Respondents from Cohort 1 who identified either themselves, or a family living in the same household to have a longstanding illness or disability (n=11), were asked 'does this/ do these health problem(s) or disability(ies) mean that you have any substantial difficulties with any of these areas in your life?' Main difficulties experienced included: 'mobility' (n=8), 'lifting/ carrying or moving objects' (n=7), 'communication' (n=6) and 'memory/ ability to concentrate, learn or understand' (n=6). For a full breakdown of results see Table 3.2.

Table 3.2. Disability status

| | | Frequency (%) |
|---|--|---------------|
| Anyone in household have any longstanding illness or disability | <i>Yes</i> | 21 (30) |
| | <i>No</i> | 48 (68.6) |
| | <i>Not sure</i> | 1 (1.4) |
| Anyone in household registered as disabled | <i>Yes</i> | 8 (38.1) |
| | <i>No</i> | 11 (52.4) |
| | <i>Not sure</i> | 2 (9.5) |
| Impact of health problems or disability(ies) (<i>Cohort 1 only</i>) | <i>Mobility</i> | 8 (72.7) |
| | <i>Lifting/ carrying or moving objects</i> | 7 (63.6) |
| | <i>Manual dexterity</i> | 4 (36.4) |
| | <i>Continence</i> | 3 (27.3) |
| | <i>Communication</i> | 6 (54.5) |
| | <i>Memory or ability to concentrate, learn or understand</i> | 6 (54.5) |
| | <i>Recognising when you are in physical danger</i> | 3 (27.3) |
| | <i>Physical co-ordination</i> | 3 (27.3) |
| | <i>Other health problem or disability</i> | 2 (18.2) |
| | <i>None of these</i> | 1 (9.1) |

Household size

Overall, the mean household size was 4.4 (range=1 to 13 people, SD=2.3). The average number of children in a household under 18 years was 2.1 (range=0 to 11 under 18's, SD=2.1). The number of people living in the household over 65 years ranged from 0 to 2 people, with an average of 0.7 (SD=0.3). See Table 3.3 for a full breakdown of results.

Table 3.3. Household size

| | | Frequency (%) |
|--|---------------------|---------------|
| Number of people living in household | 1 | 9 (12.9) |
| | 2 | 6 (8.6) |
| | 3 | 6 (8.6) |
| | 4 | 16 (22.9) |
| | 5 | 8 (11.4) |
| | 6 | 15 (21.4) |
| | 7+ | 9 (12.9) |
| | <i>Missing data</i> | 1 (1.4) |
| Number of children in household under 18 | 0 | 19 (27.1) |
| | 1 | 13 (18.6) |
| | 2 | 10 (14.3) |
| | 3 | 13 (18.6) |
| | 4+ | 15 (21.4) |
| Number of people in household over 65 | 0 | 66 (94.3) |
| | 1 | 3 (4.3) |
| | 2 | 1 (1.4) |

Language

The majority of respondents spoke Czech (44.3%), Slovak (25.7%) or Roma as their primary language. 90% of respondents reported speaking at least one other language well. Roma (51.4%), Slovak (50%) and Czech (30%) were the languages most commonly identified as alternative languages that could be spoken well by respondents. 15.7% of respondents identified English as an additional language spoken.

All respondents were asked to describe their spoken English. Over three quarters of the sample reported to speak 'little' or 'no' English. A further 14.3% spoke English 'well/fluently' and 7.1% described their spoken English as 'well/ OK' (one respondent did not answer the question). Table 3.4 provides a full breakdown of results.

Table 3.4. Languages spoken

| | | Frequency (%) |
|---------------------------------------|---------------------|---------------|
| Language most comfortable speaking | <i>Czech</i> | 31 (44.3) |
| | <i>Polish</i> | 2 (2.9) |
| | <i>Roma</i> | 14 (20) |
| | <i>Slovak</i> | 18 (25.7) |
| | <i>Other</i> | 1 (1.4) |
| | <i>Missing data</i> | 4 (5.7) |
| Number of other languages spoken well | <i>0</i> | 3 (4.3) |
| | <i>1</i> | 37 (52.9) |
| | <i>2+</i> | 29 (41.4) |
| | <i>Missing data</i> | 1 (1.4) |
| Additional languages spoken well | <i>Czech</i> | 21 (30) |
| | <i>Polish</i> | 5 (7.1) |
| | <i>Roma</i> | 36 (51.4) |
| | <i>English</i> | 11 (15.7) |
| | <i>Slovak</i> | 35 (50) |
| | <i>Other</i> | 3 (4.3) |
| Description of spoken English | <i>Fluent/ well</i> | 10 (14.3) |
| | <i>Well/ Ok</i> | 5 (7.1) |
| | <i>Little</i> | 40 (57.1) |
| | <i>None at all</i> | 14 (20) |
| | <i>Missing data</i> | 1 (1.4) |

About the area you live in

Respondents were asked to report what they felt the biggest community problem in their area was. Key issues included:

- Isolation (lack of places for Roma people to meet, no activities for the young, not feeling welcomed in the community, lack of knowledge/ services of where to seek help about rights)
- Street Cleanliness (rubbish, dog fouling, needles)
- Crime (drug use, vandalism, fear of violence)
- Unemployment

Cohort 1 were asked about their experiences of crime. 18.2% of respondents (n=8) had been a victim of crime in the last year (1 respondent did not answer the question). Crimes related to car/ property damage, fraud, theft and verbal abuse. All respondents stated they reported the crime; 3 respondents reported the crime to the police. Others reported the crime to: friends and family (n=1), landlord (n=1), school (n=1) and 2 respondents did not identify who they reported the crime to. Of those who had been a victim of crime, 75% felt it was because of their nationality.

47.7% of respondents did not feel they had, or someone in their family had, faced prejudice or discrimination whilst being in the UK because they were Roma. Conversely, 13.6% reported to face prejudice all the time (6.8%) or often (6.8%). 11.4% reported experiencing prejudice occasionally and 11.4% hardly ever. Data is missing for 7 respondents. Examples of this prejudice or discrimination experienced included: verbal abuse/ being threatened, damage to property, mistreatment from professionals and children experience problems in school.

About your health and use of health services

Doctor

91.4% of respondents were registered with a doctor, whilst 7.1% were not (1 participant did not answer the question). Nearly half (47.1%) of participants were registered with a doctor in LS8 (24.3%) or LS9 (22.9%). Other postcode areas included: LS13 (15.7%), LS12 (14.3%), LS11 (8.6%), LS18 (2.9%) and BD5 (1.4%). Data is missing for 7 respondents.

Those who were not registered with a doctor gave reasons such as 'only just having moved to the area/ country'.

Dentist

55.7% of respondents were not registered with a dentist compared to 41.4% who were (data is missing for 2 respondents).

Cohort 1 were asked why they were not registered with a dentist, the most common reason being, 'not knowing how to register' (n=14). Examples of other reasons included: 'scared', 'not got round to it', 'no problems at present', 'unsure of costs' and 'cannot find an NHS dentist'.

Pharmacy

Almost two thirds (61.4%) of respondents used their pharmacy for health/ medication services. 2 in 5 (40%) respondents used their pharmacy for multiple services. Respondents reported most commonly using their pharmacy for prescription (60%) and over the counter medicines (38.6%). Other reasons for using a pharmacy included: general health advice (8.6%), health services (1.4%) and 'other' (1.4%).

Mental wellbeing

Respondents were asked 'in general how do you feel most days?' Over half (51.4%) of respondents reported they felt 'OK' most days and a further 18%.6 described themselves as 'happy'. Conversely, 20% of respondents felt 'anxious/ stressed', 5.7% were in 'low mood/ down' and 4.3% 'sad' most days.

91.4% of respondents identified that 1 or more factors had caused them stress in the past year. On average, respondents identified 2.7 factors that had caused them stress in the last year (range 0 to 6, SD=1.4). The most common cause of stress were 'money problems' (74.3%), 'lack of money' (64.3%) and 'not being able to work' (37.1%). Conversely, 8.6% of respondents reported no factors listed had caused them stress. See Figure 3.1 for a full breakdown of responses.

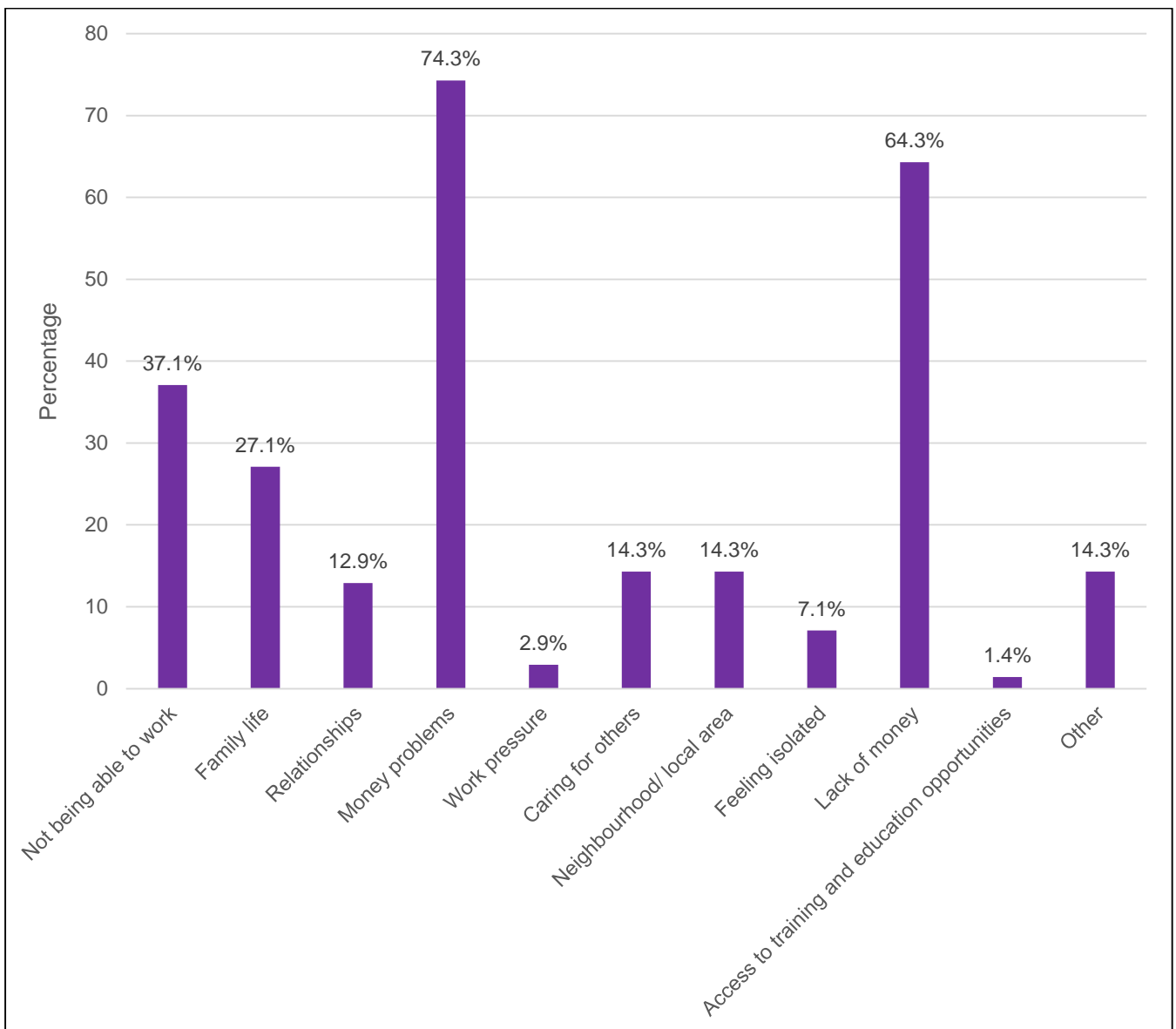


Figure 3.1. Have any of the following caused you stress in the past year?

The majority of respondents (67.1%) stated that stress experienced had not resulted in conflict, arguments or violence within the family. Conversely, 24.3% of respondents stated it had resulted in conflict and 4.3% were unsure (data is missing for 3 respondents).

Respondents who identified factors that had caused them stress in the last year were asked what they thought could be done to help reduce this. Overall, 79.7% identified one or more responses to reducing stress (range=0 to 5, mean= 1.9, SD=1.4). Over half (54.3%) of respondents felt advice surrounding money or benefit entitlement would be beneficial. 65.5% of respondents who identified money as a stressor (money problems/ lack of money), thought that advice on money/ benefit entitlement would help reduce their stress. See Figure 3.2 for a full breakdown of responses.

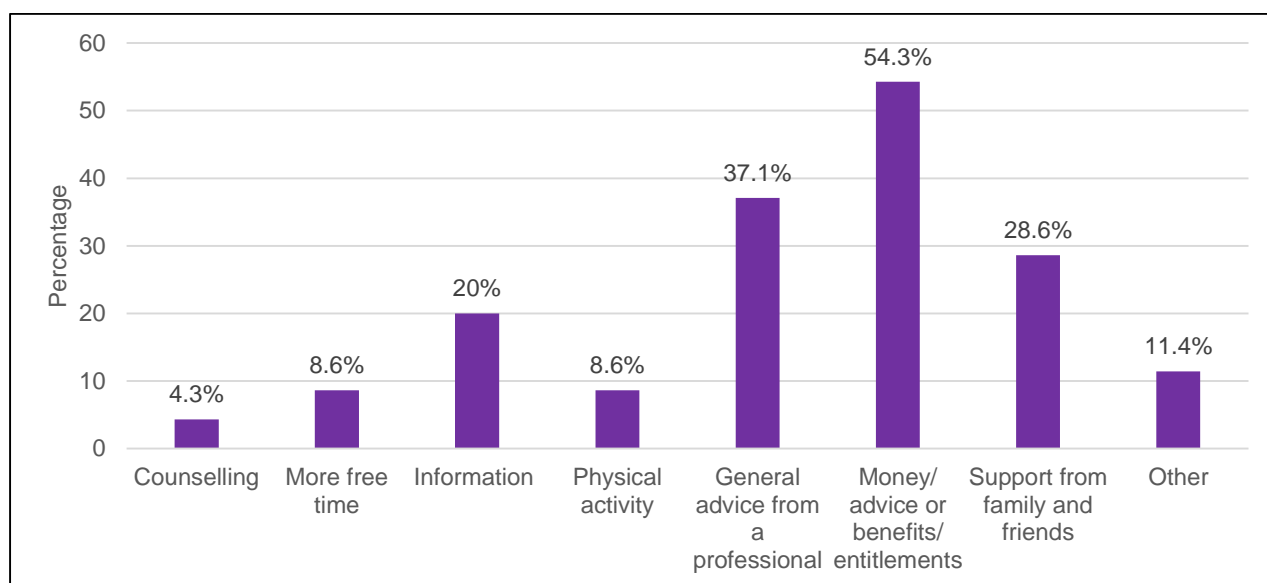


Figure 3.2. If you indicated in question 20 something that has caused you stress in the past year, what do you think could help you reduce this?

Smoking

Overall, 67.1% of respondents were current smokers, 24.3% non-smokers and 7.1% ex-smokers (data is missing for 1 respondent). 80.9% of smokers were smoking more than 10 cigarettes a day (see Figure 3.3 for a full breakdown). Of those who currently smoked, two thirds (63.8%) wanted to give up in the future.

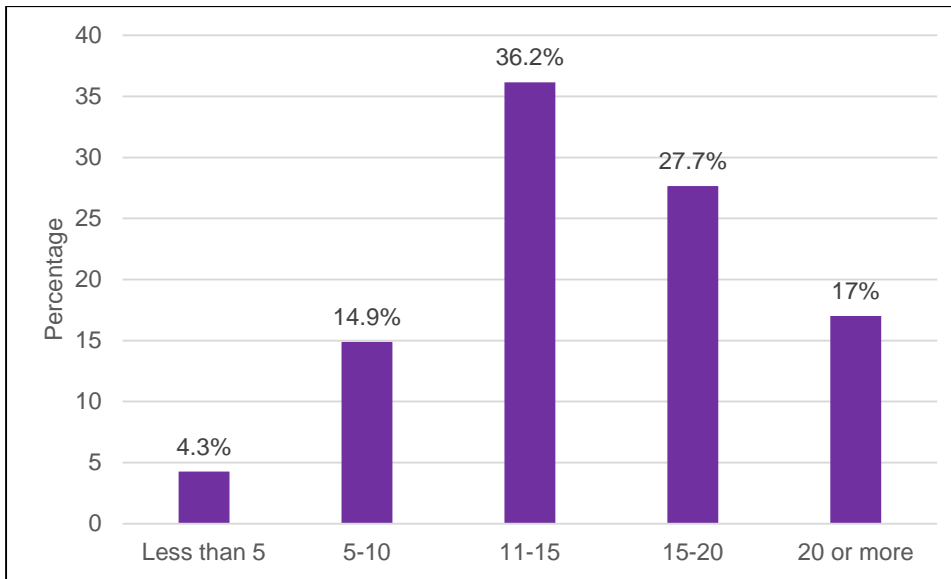


Figure 3.3. How many cigarettes do you smoke per day?

Alcohol

Approximately half (51.4%) of respondents reported they consumed alcohol 'monthly or less' and a further 40% 'never' drank alcohol. 7.1% of respondents consumed alcohol 2 to 4 times per month (data is missing for 1 respondent).

Cohort 1 were asked if they knew 'what constitutes 1 unit of alcohol?'; only 2 out of 44 (4.5%) respondents stated 'yes'. It was therefore not possible to gain any insight into what quantity of alcohol people were consuming when they did drink.

Fruit and vegetable consumption

Respondents were asked 'on a scale of 1 to 5 (1=very easy, 5=very hard), how easy do you find it to get hold of fresh fruit and vegetables?' Over half (54.3%) of respondents selected 1 or 2, and just under one quarter choose 4 or 5. A further 20% stated 3. Data is missing for one respondent (see Figure 3.4 for a full breakdown of results).

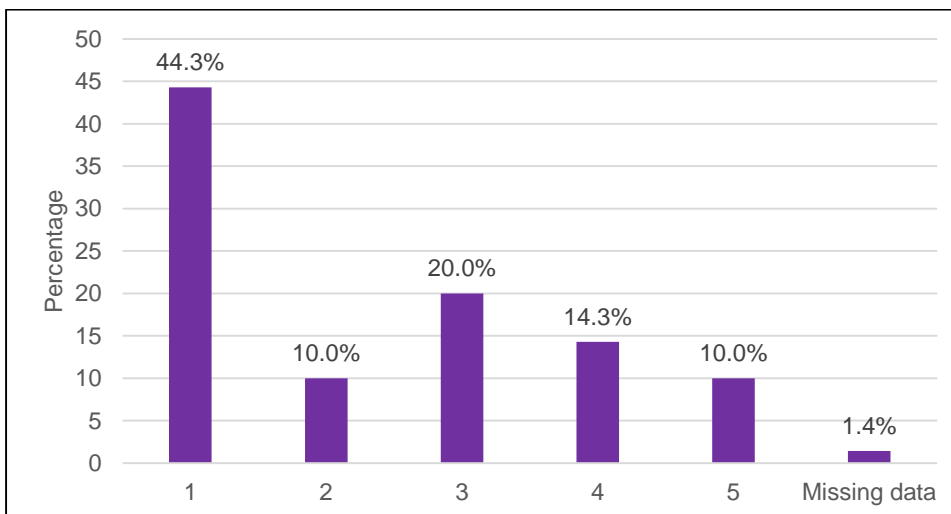


Figure 3.4. On a scale of 1-5 (1=very easy, 5=very hard), how easy fo you find it to get hold of fruit and vegetables?

When asked ‘yesterday, how many portions of fruit and vegetables did you eat?’, only 1.4% of respondents consumed the recommended daily allowance of 5 or more and 35.7% consumed none. The majority of respondents (51.4%) had 1 to 2 portions. For a full breakdown of results see Figure 3.5.

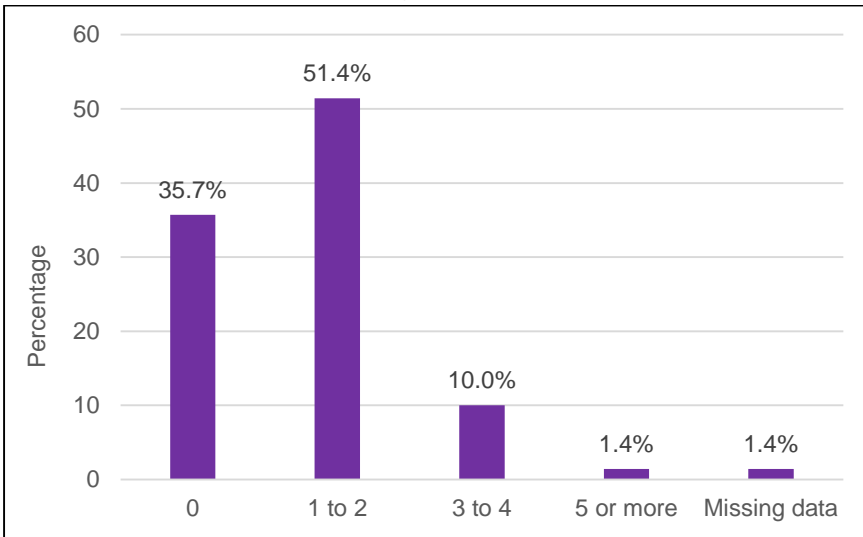


Figure 3.5. Yesterday, how many portions of fruit and vegetables did you eat?

70.6% of the sample who thought getting hold of fruit and vegetables was hard (4 or 5), consumed no portions of fruit and vegetables the previous day. However, only 1 respondent (2.6%) who stated getting hold of fruit and vegetables was easy (1 or 2) consumed the recommended 5 or more portions the previous day.

Physical activity

On average, respondents participated in physical activity at a moderate intensity (heart beating faster and slightly breathless) for 30 minutes 3.4 times a week (range=0 to 7, SD=2.7). 34.3% of respondents were physically active for 30 minutes 5 or more times a week. Conversely, 18.6% participated in physical activity for 30 minutes zero times a week (see Figure 3.6 for a full breakdown of results).

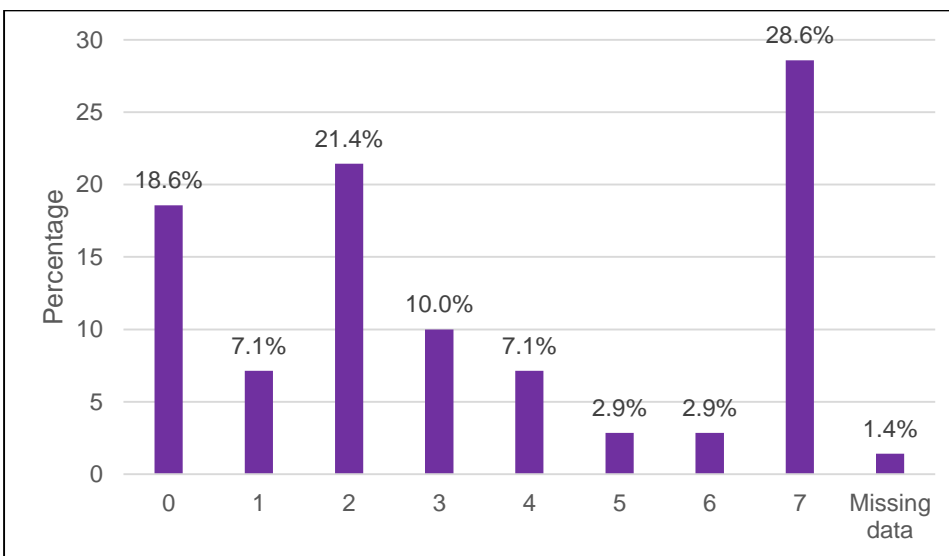


Figure 3.6. How many days a week do you get 30 minutes of physical activity that makes your heart beat fast and gets you feeling slightly breathless?

Seeking medical help or advice

Respondents were asked 'when you or a member of your family fall ill and you want medical help or advice where are you most likely to go?' On average, respondents identified 1.4 sources they would turn to (range=1 to 3, SD= 0.5). The most popular source of help was the 'GP' (80%) followed by 'friends and family' (37.1%) and 'Accident and Emergency' (12.9%). For a full breakdown of results see Figure 3.7.

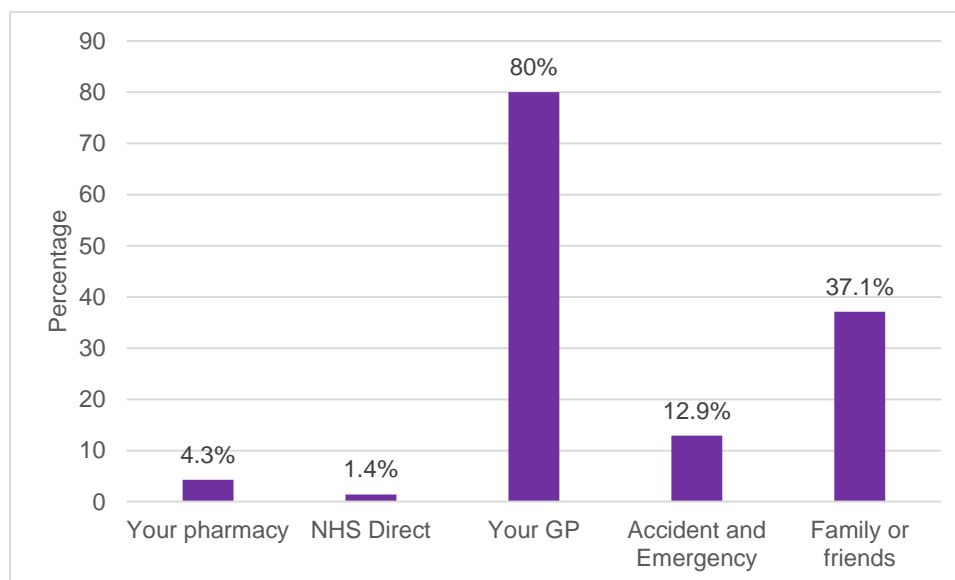


Figure 3.7. When you or a member of your family fall ill and you want medical help or advice where are you most likely to go?

Only Cohort 1 were also asked about seeking support for sexual health concerns. Data showed over three quarters (77.3%) of respondents would seek support from a 'GP' if concerned about their sexual health and a further 9.1% would visit a 'local sexual health clinic'. Other sources of help respondents would consider included CaSH (Family Planning Clinic, 2.3%) and family/friends (2.3%). 4.5% of respondents did not know where they would go and 4.5% stated 'don't use' (see Figure 3.8 for results).

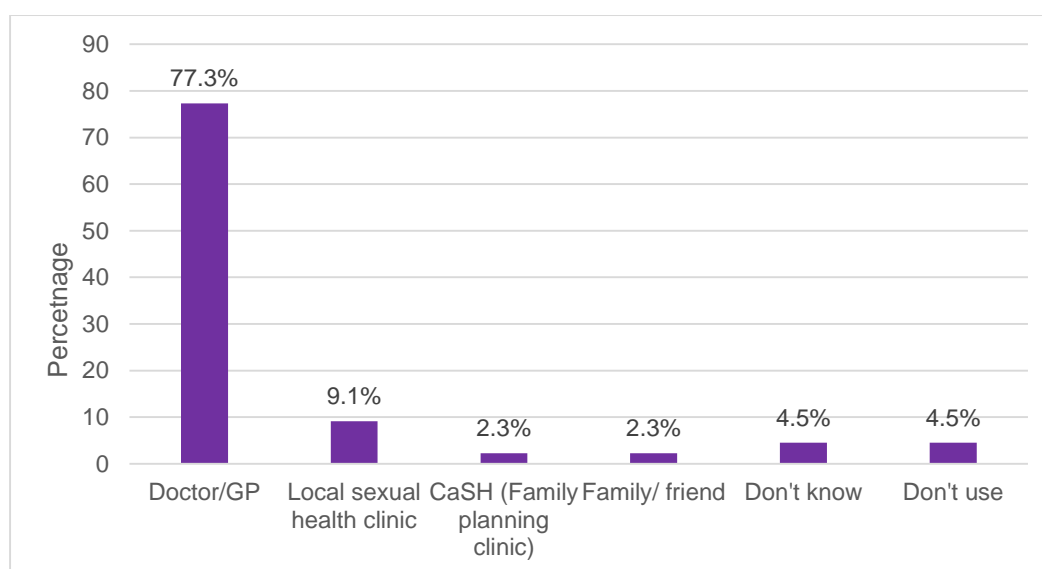


Figure 3.8. Where would you go if you were concerned about your sexual health?

Respondents (from Cohort 1 only) were asked about their awareness of various immunisations services and screening services. Awareness of immunisation services varied; awareness of the childhood immunisation programme (88.6%) was highest, followed by the seasonal flu vaccination (45.5%), HPV vaccination (29.5%) and pneumococcal programme (15.9%). 6.8% of respondents were not aware of any vaccination programmes. See Figure 3.9 for a breakdown of results.

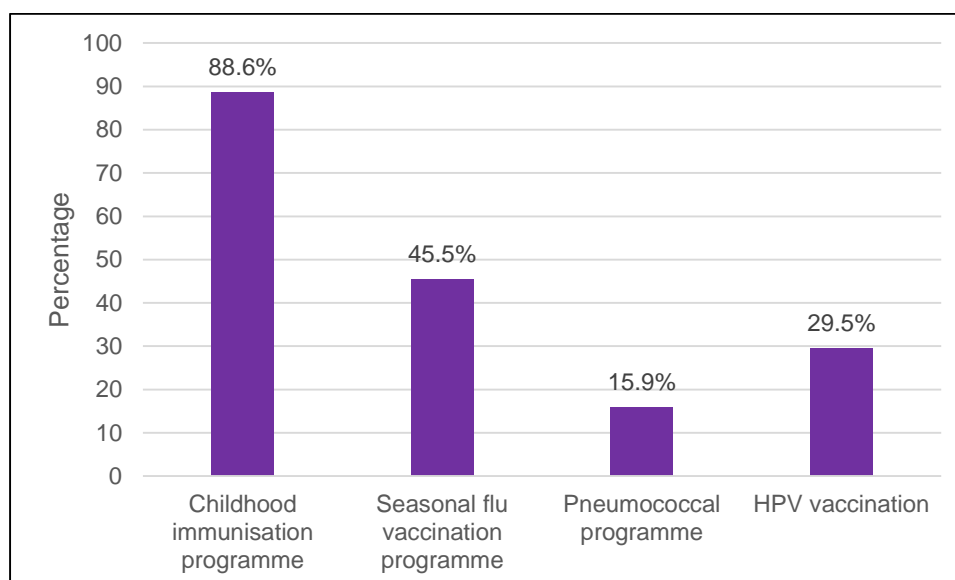


Figure 3.9. Are you aware of the following services or immunisations?

Similar to awareness of immunisation services, awareness of pregnancy/ childhood screening programmes was highest (new born screening, 77.3%; anti-natal screening, 59.1%). Awareness of abdominal (18.2%) and bowel (20.5%) screening programmes was the lowest. 18.2% of respondents were not aware of any of the screening services listed (see Figure 3.10 for a full breakdown of results).

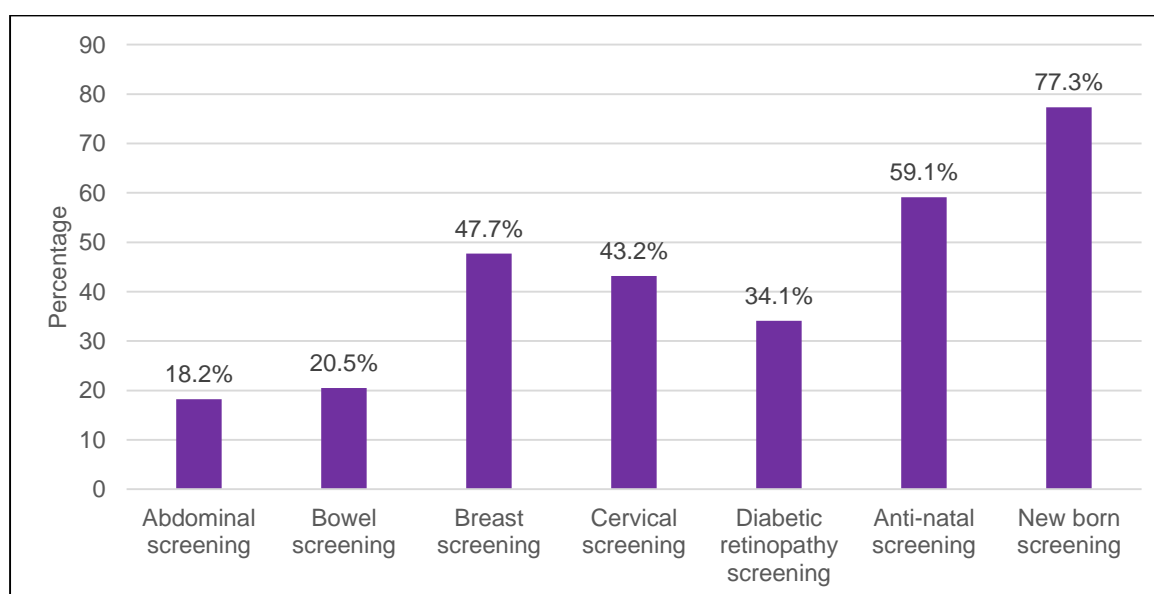


Figure 3.10. Are you aware of the following screening programmes?

The majority (75%) of respondents (Cohort 1) were not aware of NHS health checks which looks at the heart health factors. Only 18.2% were aware of the checks and 4.5% were unsure (2.3% did not answer the question).

When asked if respondents experienced any barriers to accessing the immunisation and screening services the most commonly cited problem was language barriers.

About your GP/ Doctor

Overall, 41.4% of respondents described the service they received from their doctor as 'good' (31.4%) or 'excellent' (10%). A further 35.7% thought the service was 'OK' and 15.7% described it as 'poor' (data is missing for 5 respondents).

Main reasons for rating the service as 'excellent' or 'good' included: satisfaction with service received, as well as professional and personal care. Example reasons for describing the service as 'OK' or 'poor' were: not feeling heard, dissatisfaction with diagnosis/ treatment/ referral, lack of time spent with patient as well as language barrier/ no interpreter present during appointments.

Respondents from Cohort 1 were asked 'what are the good things about your doctor and their service, what do they do well? Main strengths of the service included: personable/ helpful service, provision of interpreters, appointment system and appropriate examinations/ diagnosis/ treatment.

Respondents (Cohort 1 and 2) suggested the service could be improved by having an easier booking system, providing an interpreter, spending more time with patients and improving communication

Other issues that made it difficult for respondents (Cohort 1 only) to use their doctor and their service included language barriers and appointment system.

About hospital services

57.1% of respondent had used hospital services in the last 12 months, 41.4% had not (data is missing for 1 respondent). 41.4% of respondents had accessed the hospital 1 to 2 times, 4.3% 3 to 4 and 11.4% 5 or more.

Of those that had used the hospital in the last 12 months, over half (56.1%) felt the service they received was 'good' and 9.8% described it as 'excellent'. Conversely, 14.6% described the service as 'very bad' (2.4%) or 'poor' (12.2%) and 17.1% as 'OK/ indifferent' (data is missing for 1 respondent).

Reasons for scoring the services received as 'excellent' or 'good' included: satisfied with service received, personable staff, the provision of interpreters, clear explanations, good facilities, speed of service and easy to navigate. Those who said service was 'indifferent/ok', 'poor' or 'very bad' gave the following reasons: waiting time, no interpreters provided/ language barriers and dissatisfied with care.

Respondents from Cohort 1 were asked 'what is your hospital doing well? Main strengths of the service included: treatment/ service and information/ explanations provided.

Respondents (Cohort 1 and 2) suggested the service could be improved by reducing waiting times, having more staff, providing interpreters/ language support and employing Roma staff.

Other issues that made it difficult for respondents (Cohort 1 only) to use their hospital service included: language barriers, difficult to navigate and problems travelling to the hospital.

Language needs

77.1% of respondents reported 'always/ most of the time' (45.7%) or 'sometimes' (31.4%) finding language a problem with using health services. A further 17.1% reported languages as 'hardly ever' (5.7%) or 'never' (11.4%) being a problem (data is missing for 4 respondents). For a full breakdown of results see Figure 3.11.

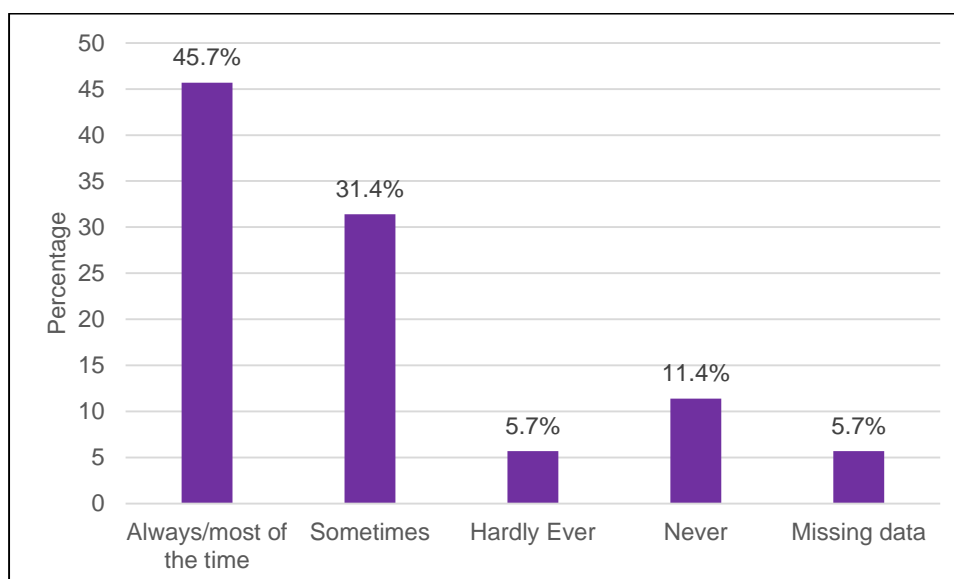


Figure 3.11. Do you find language a problem when using health services?

Those that experienced language a problem when using health services 'always/most of the time' or 'sometimes', were most likely to rely on 'telephone interpreting' (38.9%), 'family and friends' (33.3%) or an 'interpreter' (31.5%) for support when using the health service. A further 9.3% reported they would most likely rely on a 'bilingual advocate'. One respondent stated they would rely on 'no-one'.

Respondents from Cohort 1 were asked additional questions regarding language needs and health service, including:

- Do you feel you understand the advice given to you?
- Do you feel able to ask questions or ask for more information?
- Do you feel you have a say in the decisions made about you?

Overall, the majority of respondents reported 'always/ most of the time' or 'sometimes' to each question. Specially, 56.8% of respondents 'always/most of the time' understood the

advice given to them; 54.5% 'always/most of the time' felt able to ask questions or ask for more information; and 45.5% felt they 'always/most of the time' had a say in decisions made about them. Conversely, 6.8% of respondents 'hardly ever' (4.5%) or 'never' (2.3%) understood the advice given; 11.4% of respondents stated they 'hardly ever' (9.1%) or 'never' (2.3%) felt able to ask questions or ask for more information; and 18.2% felt they 'hardly ever' (9.1%) or 'never' (9.1%) felt they had a say in decisions made about them. See Figure 3.12 for a full breakdown of results.

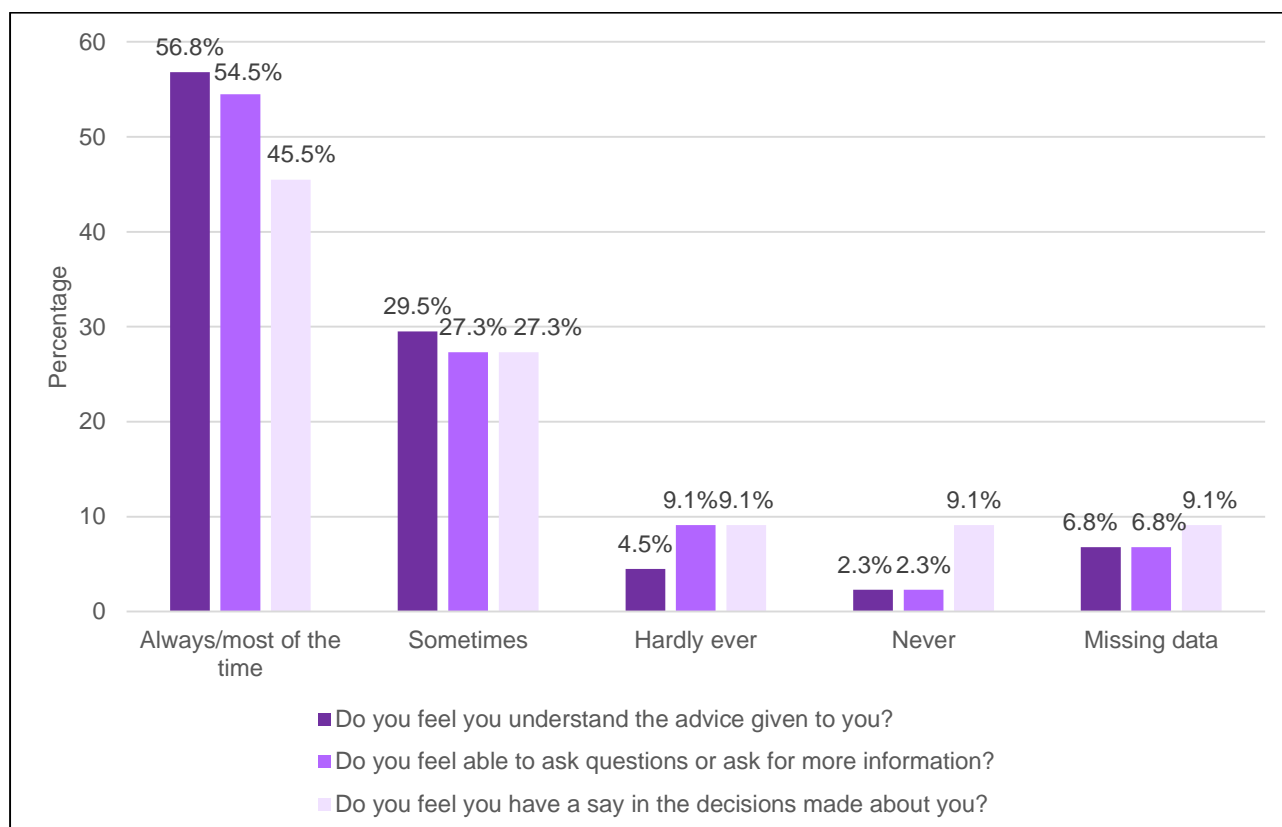


Figure 3.12. Language needs within health services

Other

Cohort 1 respondents were asked 'In your opinion what one thing could health services do differently that would make the biggest difference to you, your family and the Roma community?' The most common answers were provision of language support through the use of interpreters, employing more workers from the Roma community and having information readily available in different languages.

"To employ people from Roma community in NHS and interpreters". (Questionnaire respondent)

Qualitative findings

This section presents the main themes emerging from the interviews with professionals and the focus groups with the Roma community. The feedback has been combined as the emerging themes were broadly the same. Direct quotations have been used to illustrate the themes discussed and to give participants a voice.

Housing

Professionals explained that many members of the Roma community have to use private landlords who are reluctant to provide facilities, or make repairs to the houses. Poor living conditions such as damp and draughty accommodation were believed to be stressful and harmful to health. One interviewee noted that home addresses for the community change rapidly indicating people are staying in housing on a temporary basis which can impact accessing services such as registering for the GP or receiving letters about appointments.

It was emphasised that housing for Roma was of poor quality, whereby they would be exposed to often dirty properties that lacked proper facilities.

“...The bad things here in Leeds is that the houses that are available to rent, they are in a bad state, and it is not hygienic...”

“...for over a year, we have damp in our house, water is seeping up from underneath, we went to housing last year, we reported it...they would repair it...”

One participant stated that they used their own money to repair their house when their landlord refused.

“...the house where I live, the repairs on it cost me almost £1500. Because I didn't pay any deposit. But if I move out, who's gonna give me back what I put in? Nobody! So I'm just repairing the house for its owner. But I had to do it, because I was thinking about my kids.”

It was reported that few landlords would wait for housing benefit to be granted therefore there is a dependence on private landlords who can demand cash in hand deposit and rent. This can prove problematic for people to find large sums of money which can lead to borrowing money. It was noted that language barriers can prevent Roma families from accessing information around housing entitlement rights and tenants protection.

Work

One theme to emerge was the difficulty of securing employment. Lack of work/being unable to work and the financial difficulties this brings were highlighted as one of the main causes of stress. Work is seen as important to health and participants indicated they wanted to work. It was acknowledged that finding work is extremely hard, particularly during a recession and it was highlighted that being able to speak English was a key enabler to finding work.

"I would just like to go to work. When you work, everything changes... Work would be best, if I had that, I wouldn't have to think about things. No? When you have a job, you're better off. If you don't have a job, you're not entitled to anything."

For women who wanted to work childcare was indicated as a barrier to finding employment:

"I had a chance of working in Tesco but I was disadvantaged because I would have to start at 10 and work until 7. And that was no possible for me because my children come home from school at 3:10 or 3:20"

Money and bills

Participants expressed mixed levels of difficulty with money, some were able to pay their bills but most struggled to pay everything on time and sometimes fell behind with payments. Paying in instalments or taking out loans are a popular way of managing the situation.

Participants discussed trying to spend less and 'being careful', food and clothing were the items most likely to be cut back on with children's needs being prioritised:

"Yes, I have to be more careful and spend less, for example I can't buy clothes or household items or something, I have to make do because fridge is something you need to have...you can cut back on food, on clothing, and other things like this."

Participants were reluctant to cut back on heating (despite the costs of fuel) as they associated the cold with having negative impacts on health particularly for children.

Reforms and benefits

Participants talked about the impacts of new reforms on the community in relation to how people came here to try and find a better life. They expressed concerns that the economic climate is affecting everyone but is likely to have a bigger impact on those in lower paid, less well regulated, less skilled jobs. In conjunction services who are trying to support people in these situations are facing budget cuts. Concern was expressed that new welfare reforms and changes to benefits were likely to have a large impact on Roma. Participants explained they find the prospect of being out of work with little money daunting as they fear having to return to their country of origin.

"That's very bad, people are worried. To say it in one sentence. It is a nightmare for me, the thought of having to go back home. That is the one thing, the one thing that I do not want to think about. That's why I want to try to apply for citizenship this year."

"It is getting worse because many people are on benefits and benefits will be getting capped...if they lose their housing benefits as well, landlords will want to evict them...We will be homeless, same as back home."

Professionals felt that the introduction of universal credit would mean many families would struggle and that people needed help most with benefits, money and food. It was felt that people experienced stress when living in poor conditions and when thinking about how to

provide for their family. It was felt that families would buy food that would last a long time with long expiry dates rather than investing in fresh healthy food as fruit and vegetables were expensive.

Roma participants expressed they wanted more information about their rights. They accessed information from; other Roma, the Inland Revenue, the internet or Sure Start centres, but they stated more information was needed. There was an acknowledgement that trying to access information was difficult if English abilities were not good. Some people worried about asking and not being able to talk in English. This was a barrier to the community being empowered and able to access information themselves.

“People have very little information, in every area. Anywhere you go, to any agency or office, no one ever tells you ‘ you are entitled to this and this and this’ and lets you decide. No-one tells you what you are entitled to...you have to calculate everything and try to get information from where you can, and then you can go and complain...people have very little information.”

Discrimination

Discrimination was discussed by a number of the professionals (Roma professionals were able to bring perspective as service providers and service users). Generally it was felt that the type of discrimination in this country was different as open discrimination is discouraged by the mix of people who work in the UK:

“...in any office, housing office or other places, there are Indian people, Pakistani people, English people, black people all working there. And people sit at desks next to each other. So over here they cannot be any discrimination when you go to an office [local authority office], because next to the person dealing with you, might be their colleague who is black. So they would discriminate their colleague at the same time as you.”

Some focus group members felt the health services treated them with dignity and respect, and expressed that they felt less discrimination in the UK.

“...there isn’t such discrimination here, if you are looking for work, you will find work.”

There is a sense that Roma in Leeds struggle to leave behind their past experiences of feeling unheard, receiving a second class service and discrimination in their country of origin. It was felt that this could provoke a perception that old patterns of discriminatory practice within services and society could surface in Leeds.

“Yes yeah and I think that comes back to that discrimination thing if you are used to being dismissed and getting a second class service then if you feel you are not being listened to, than you are not going to react well to that are you so you are going to be particularly sensitive to feeling like you are being fobbed off.”

It was suggested that Roma mistrust migrants from different locations feeling they hold particular prejudices.

“I had an interpreter, a Czech one, I also had a Slovak one, but it’s always better to have a Czech one than a Slovak one. They don’t have, it really is true, they don’t’ have

the prejudice, and even the attitude when they meet you is completely different than if she is Slovak. Slovak interpreter arrives, her nose up and hardly says anything to you."

One participant explained her reluctance to disclose that they are Roma to avoid this discrimination:

"My daughter goes to school but I don't put her as a Roma, because the Slovak children there would laugh at her. Because Slovak children go there as well. 'Hey, look, Gypsy."

This was echoed by a professional who stated: *"if you asked staff in their service whether there are a lot of Roma here they would say I don't know but we have lots of Czech."*

Disempowerment

The data indicated that the Roma may be feeling disempowered due to language barriers and a lack of understanding of the systems in the UK.

"Yeah I think a lot of it is because the system here is so different to the way things work back home. Even people that speak English probably at first struggle to understand and then if you add the language problems, you might feel like you are not being listened to."

It was suggested that this lack of understanding has led to some Roma feeling disempowered to help themselves and it was highlighted that Roma interpreters should be given a chance and a more predominant role.

"But I think that there should be Roma interpreters a Gypsy, or a Roma, he speaks perfect English and can read and write as well, he should be given a chance. He should be given a chance [...] you can imagine that there would be interpreters among Roma."

Some participants expressed that they believe some Roma are afraid to go to areas where it is predominantly English as this can relate to how educated someone is or knowing how to behave culturally.

Community tension

Community tension was discussed in relation to interactions in healthcare settings for example a waiting room. The use of family or community members for support of language or understanding the system, coupled with systematic differences between the UK and their countries of origin means Roma could present for medical appointments as family groups. These groups can be noisy and can be intimidating or offensive to others which can lead to them being excluded from areas. One interviewee reported that staff are often aware of the issues that people may have faced in their countries of origin, which can account for some of the more challenging behaviours and interactions in these settings.

"...so if they want something and you say not then they assume you are saying no because you are discriminating against them rather than because actually no is the right answer in that situation erm and some of the quite demanding and confrontational approach, especially at reception, again you kind of imagine it's because people have had to fight, if they need something they can't just get it, they have to fight for it so therefore they come ready for a fight or ready for a battle."

Barriers to access: GP services

Some participants expressed that they were used to accessing GPs quickly and found it difficult to adapt to the UK appointment system. Lack of telephone interpreters when booking GP appointments and only being able to book appointments over the phone caused problems with making appointments for some people, particularly if they do not have a family member or friend who can phone on their behalf. There is a general perception that GPs do not want to provide interpreters. Professionals interviewed identified that not understanding the health system and particularly to book into the right kind of slot (emergency vs routine GP appointments) was also a problem and this was compounded by language barriers.

Some participants said that in their country of origin it was easy to get a more thorough check up and examination when visiting a GP. There was a view that visits to GPs often end in prescriptions of pain killers and not being referred to a specialist.

“The only thing is that I have to beg him [GP] to send me to see a specialist, when I need to see someone, like a dermatologist or someone else. That takes a very long time. I’ve been going to see my GP for four years, he knows my diagnosis, but still, when I need to see a specialist, I have to go there [to the GP] ten times before he refers me.”

A resounding theme that emerged was children not being prescribed medication when presenting with symptoms that the Roma parents considered potentially dangerous. It is not possible to determine from the data whether children are genuinely presenting with viruses for which antibiotics will not help, and the Roma parents do not understand this, or if there is a break down in care. What is clear is that the lack of understanding is building suspicion and feelings of not being heard.

“Well, what I do is, when one of the small children is ill, is coughing, I don’t take them to the doctors. Why? It’s pointless. So we know that nurofen or ibuprofen also has anti-inflammatory effect. So I buy ibuprofen or nurofen and I give them that.”

While there was some negative connotation around GP services some participants expressed their appreciation of; drop in sessions, being seen in a timely fashion and having a choice of appointments.

“They have a service that if you turn up between 8-9, they will see you, you don’t have to make an appointment, but if I want to make an appointment, I call them and get an appointment.”

Views about GPs themselves were mixed. Positive focuses tended to be around GP interaction with members of the Roma community:

“Well, yeah, the doctors are good, that’s fine, if I need anything, they’re always very helpful.”

“The service that we received was as we’d expected.....They helped us as they should, they gave our daughter what she needed, and thank god, she got better, so there were no problems.”

Hospital services

Some of the professionals emphasised the length of time it takes to navigate through the system, from getting a GP appointment, getting a referral to a specialist, waiting for an appointment and being seen in hospital is contributing to members of the community presenting at a late stage with diseases.

Appropriate usage:

The majority of respondents attributed the use of A&E within the Roma community to the following: feeling there is a lack of examination, not being referred to a specialist combined with a lack of language support, leading to mistrust, self-diagnosis, results in going directly to A&E. Some participants stated they find it hard to get a GP appointment others suggested that if they could not get a GP appointment they would go to A&E. This raises the question of whether people are presenting inappropriately at A&E and could also suggest that awareness of the walk in centres or alternatives to A&E may need improving.

“So what would you do if you can’t get an appointment with your GP? And your child is very ill or you feel very ill, where would you go, to the hospital?”

I would go to A&E, would have to, there’s no doubt, to A&E, yeah, that’s the only option.”

Waiting times in A&E were a recurring source of concern for members of the Roma community but they stated they felt everyone was treated the same in A&E and there was no distinction between the Roma community and the English. The concern around waiting times could be associated with the confusion about prioritisation in A&E and a clear lack of understanding of how the system works.

“Priority? Nobody has any priority there. You could be dying there and you don’t get a priority.”

“But it’s the same even with English people, it doesn’t matter if it’s English people or whatever... he was bleeding and he was waiting there for three hours.”

Treatment and care:

Positive comments about hospital services centred around feeling they were treated well, feeling the doctors were more approachable than ‘at home’. Being provided with interpreters and clear directions were also appreciated as was the standard of care. Two participants expressed satisfaction with care that their children received:

“When my eldest daughter had to have an operation, and she understood a bit more...she knew that she was going to have an operation, they played and distracted her so that she wasn’t even aware that she was about to have an operation. So she didn’t even know. They were very nice to her...and they could see that I was worried, because I was crying, so they looked after me as well...”

“They treat me and my children very well. I can’t complain. Back home, when I used to go ...my little boy...he can’t walk, and back home, when I used to go with him to the physio, he was not allowed even just to touch a toy... It’s not like that here. He just

plays with whatever he likes, they play with him, as they want... They teach him, through play, the exercises that he needs to do."

In one focus group participants gave indications that they believe antenatal care was better 'back home' and expressed some concern over how gynaecological care worked in the UK particularly that the amount of routine checks in this area was lower than in their country of origin.

"I also know some people, that the mothers have older daughters who are pregnant, and they go back home before their due date, that the care here is not good."

Participants often compared the care they received in the UK to care they accessed in their country of origin:

"Another thing that I think is not very good here... if a woman has any problems, for example with pregnancy, and she goes to see her doctor, and she has to go to the same place as men. If she really has problems, and she has to be there in the waiting room, and everyone is sitting there looking at her, that is sort of stupid over here. "

Whilst there were some negative comments relating to the health care system, participants appreciated having access to free healthcare and exemptions from prescription charges. This meant that many people were able to access treatment that they would not be able to afford in their country of origin. '

"All the operations I had to go to with my little boy, and all the tests he's had here...back home, that would cost a fortune...I would never be able to pay for all that back home."

Language barriers

Language barriers were highlighted as a key theme to emerge when accessing GP and Hospital services. Participants discussed the problems that occur when interpreters are not provided at the point of accessing the GP. It was clear provision is very variable as some people stated that they had no problems accessing a GP. Participants felt that this was less of a problem at the hospital although there are still some people who felt they needed more support. It was highlighted that a lack of language support led to friends and family members being used as informal interpreters.

"..am the only one with some English in my house, so if something happened and I wasn't at home they could even die, because they won't get an interpreter on the phone."

This was sometimes described by research participants as a stressful process and led to increasing concerns around not understanding what is being said.

"Yeah, with the appointments. I had problems with that, because I don't speak English, they don't give interpreters over the phone, but like, my son can call them so it makes it a bit easier, but not always on the same day. So I would really like to change that."

Language barriers deterred people from being able to describe symptoms or understand diagnosis of the GP.

“But when I go there, sometimes they don’t give me an interpreter. I say, ‘Please, give me czech interpreter’, ‘No, is good, you speak’, like....that they can understand me a little bit. But I don’t know how to explain to them what it wrong with him...”

Members of the community indicated they would struggle to explain to the doctor what was wrong with them and even if an interpreter was provided sometimes it was still a struggle as the interpreters did not always know how to explain it properly due to medical terminology.

“But the biggest problem for me is English. Because back home, it wasn’t a problem for me to deal with anything. But over here, it’s difficult becauseyou have to rely on another person... And that’s very stressful...”

Another issue with language support included sending an interpreter who spoke the wrong language or did not interpret what was being said:

“We have had the odd few that aren’t very good I have to say. Yeah which don’t interpret, they don’t really relay the information back correctly and it’s a bit so I think if you use the same it’s better. It’s better for the families. Families then feel more comfortable because they build relationships with our interpreter.”

However people did know they could refuse or request particular interpreters, they also felt they could ask people to explain things again. It was acknowledged that there is lack of funding to provide interpreters, particularly face to face interpreters, and to provide paperwork in alternate languages.

The Job Centre was mentioned as somewhere else that getting an interpreter was difficult. Dentists not providing interpreters meant people had to take their own, or a family member. However, the housing office was good at providing interpreters. Some respondents explained they had been told they could not have an interpreter because they have been resident in the UK long enough to have learnt English or that they speak enough English.

“I went to sign on today, and I’ve only been here a short time, here in Leeds. But my documents show that I’ve been in England for fifteen years and they never give me an interpreter, anywhere I go. I told them that I spoke English but not perfectly, and they said, ‘no, you’ve had your NI number for fifteen years, you’ve been here for fifteen years’. They wouldn’t give me an interpreter. So every time I go somewhere, I understand some things, and other things I just have to deduct, I just have to imagine [what they’re saying].”

Learning to speak English

Participants expressed a wish to learn English but faced barriers to this such as courses aimed at an inappropriate level, having to work when courses were available and childcare.

“Like, I know that it is difficult for some families, for example my wife can’t attend courses, because of our children. She’s a housewife. But it helped me, I went to college and when I came home, I taught my wife.”

Professionals raised the importance of having basic English and the difficulties faced when trying to attend courses where there are no teachers who speak Czech or Slovak to explain what is happening. Acknowledgement was given to the importance of helping people to learn English so that they can integrate better and also how much Czech or Slovak speaking assistants or tutors on English courses can help.

Lack of understanding of health messages

Participants seemed suspicious of health messages although they seemed to understand that drinking, smoking and a poor diet is unhealthy, however they do not necessarily adhere to these messages. Participants appeared to have strongly held belief systems about these topics:

“I think that if you have a pint a day, it does not cause any harm, for example some people take pills to aid their digestion, but if you have one pint, you wouldn’t need the pill.”

In a discussion around physical activity participants expressed the belief that your body shape is fixed so exercise and diet have little to play in weight gain.

“Definitely, look at me, I go to the gym, I don’t eat sugary food, I have a normal diet. I don’t eat fatty or sugary food and I am not slim. She [points to another female] eats everything and she is slim. It doesn’t matter [what you do], I think it is just given. More or less.”

Time and money were highlighted as barriers to taking exercise. The following examples were suggested to engage people in more exercise; specific classes aimed at age groups or gender, clean parks with benches and free swimming lessons.

Mental health

One participant explained that being unable to work due to ill health was causing great concern and stress leading to poor mental health. They explained that within their community there was a fear of disclosing a problem relating to mental health:

“Yes, it is, people are worried. They are afraid to speak up, because they think that the English will tell them: ‘Well, if you are not happy here, what are you doing here?! Go home.’”

This was further reflected in professional interviews where it was felt that mental health needs were not being addressed due in part to stigma and attitudes toward mental health in the country of origin.

Smoking

During interviews with professionals from the Roma community, the high mortality of the Roma community was highlighted. It was suggested that lifestyle in the Roma community was different to other communities leading to high rates of smoking and alcohol consumption. Focus group participants did not perceive smoking to be a large problem and stated that smoking cessation remedies do not work and that stopping smoking requires willpower.

“I’d stop smoking, but why when the medication I take has so many side effects that are bad for me. So how will stopping smoking help me, when the medication, that I have to take for the rest of my life, is killing me.”

Food and Alcohol

Participants in the focus groups did not report drinking large quantities of alcohol often. However some did mention having a drink or two every day and it was acknowledged that increased stress levels could lead to alcohol consumption.

“When you’re under some stress, it can have bad effects, because you can start drinking.”

The topic of food was not fully debated however it was suggested that the participants were not eating 5 fruit and veg a day and their diet was influenced by what people desire rather than what was healthy. It was noted that fruit and vegetables were expensive and that money was required to lead a healthy lifestyle. However one professional suggested that the Roma community did not understand how to lead a healthy lifestyle. In addition, there seems to be a lack of interest in changing lifestyle behaviours while Roma prioritise finding employment, housing and schools for their children.

“The reason that many people do not know about healthy lifestyle, they don’t know what is a healthy lifestyle.”

Drugs

Drug use was highlighted as an emerging problem within the Roma community. Drug use was linked to stress and escapism from poverty, particularly among the younger generations.

“I think it’s a bigger problem than alcohol...Because they’ve learnt it and now our children can learn it from them.”

“No it didn’t used to be as much. It has started recently. There are many people now [using drugs]. There is a lot of stress because of everything...it is hard...there are many people using drugs now.”

Ill health and schools

Some participants drew a link between the difficulty of booking GP appointments and problems with school attendance. There was a need to prove children had been absent from school legitimately due to ill health, but their inability to get a GP appointment prevented them from getting letter from their doctors.

“...it’s the same with the children. They get poorly, they can’t go to school, but by the time we get an appointment, they are already feeling better. And then we don’t have any medical note to show in school.”

Interviews with professionals indicated that cultural differences influenced the dynamic of school attendance and the need to get a GP appointment.

“It is different, culturally. When you get ill back home you tend to stay at home for the week not like here”.

Another professional explains how past experience may affect school attendance in terms of life expectations. They discussed trying to raise awareness of the importance of school attendance in allowing children the best opportunity for the future:

“They have brought a lot of baggage here from Slovakia, and it won't disappear in one year, two years, but they are starting to realise. Because for example they ask me: “how did you get this job?” And I discuss with them, why is it like this, why children need to go to school, for example they say...[pause] for example I tell them ...[pause] well, we talk about how in England there are different opportunities, if children go to school, if someone has good results, doors are open for him everywhere.”

What can health services do to help?

The main areas of need were around provision of language support, more workers from the Roma community and more information particularly in their own language and use of pictures appropriate to the subject would help.

3 Discussion

The legacy of Roma history is one of discrimination, hardship, poverty and poor health outcomes. Common issues highlighted within the literature illustrate suspicion of authority figures within Roma communities, extreme poverty, poor living conditions and generally lower life expectancy than population averages within chosen countries of residence (Parekh 2011). Thus, existing evidence shows that many Roma communities have received little attention in relation to their health requirements despite a large evidence base that illustrates how the Roma community suffer from poorer health and unhealthier living conditions when compared to majority populations (Masseria, et al. 2010) and that their poor health can be closely linked to the wider social determinants of health (Foldes & Covaci 2012). The research findings reported here broadly relate to the existing evidence base in that the wider determinants of health such as employment and housing conditions were reported as key concerns by those involved within the research. Rechel et al (2009) argue that access to health care for Roma communities simply cannot be discussed without an analysis of poverty, restricted access to education and social exclusion based upon European research with children. Language barriers were also reported as a significant issue in the research findings here.

This research has also provided some insight into the use of health services, Roma community experiences and perceptions of these, as well as some detail about Roma community needs. There is a large gap in the academic evidence base here, with published research on the health needs of the Roma population being sparse (Hajioff and McKee 2000), hence this research is a useful starting point for enhancing understandings of Roma needs within the communities of Leeds.

4 Conclusion

This research illustrates that Roma community members require support in a number of areas such as with language, in terms of understanding their rights and entitlements, with work and money advice as well as with increasing their understanding of how health services work. The wider determinants of health were important factors in relation to living conditions (community issues, housing and welfare in particular), and in relation to levels of self-reported stress within respondents. Health services were perceived in a variety of ways, both positively and negatively by those who had accessed with these views related to language issues, expectations and understandings of the provision. Health behaviour data reflected high levels of smoking and low levels of fruit and vegetable consumption.

4.1 Recommendations

- Given the issues reported here in this small-scale piece of data collection attention needs to be paid to;
 - The language barriers that exist and the need for associated language services, levels of literacy and the development of appropriate communication tools. In particular language support should be given attention in relation to health service provision.
 - The need for education about health care provision, points of access and healthy behaviours. Interventions should focus upon increasing Roma access and understanding of the nature of services and treatment.
 - Employment options and related support for Roma community members should be considered as mechanisms of support and ways of tackling the wider determinants of health.
 - Localised support (for example from third sector organisations who are able to deliver outreach) would be a useful tool in addressing some of the other needs identified within the research e.g. housing and welfare benefit advice.
 - There is also now an increasing requirement to consider the health needs of the Roma community within the broader requirement of the health needs of other migrant Communities, reflecting the population changes in Leeds.

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6 Appendices

Appendix 1: Long Survey



The Roma Centre



Roma Health Needs Assessment

Advocacy Support, the Roma centre and NHS Leeds are working together to improve access to services and to improve the general health and well-being of the Leeds Roma community.

Everything you say will be treated in total confidence.

Your personal details will not be passed on to Leeds City council, NHS Leeds, GPs or any other organisation.

This survey cannot be used to affect any benefits or payments you may be receiving.

For office use:

Interviewer(s) name(s):

This survey is for members of the Roma community only

About you

| | | | | | | |
|---------|------|--|--------|--|-----------|--|
| Gender: | Male | | Female | | Post code | |
|---------|------|--|--------|--|-----------|--|

| | | | | | | | | |
|-----|-------|--|-------|--|-------|--|-------------|--|
| Age | 18-30 | | 31-50 | | 51-64 | | 65 and over | |
|-----|-------|--|-------|--|-------|--|-------------|--|

1. How would you describe your Roma community?

| | | | | |
|------|--|-------------|--|--------------|
| Roma | | Vlacho Roma | | Other state: |
|------|--|-------------|--|--------------|

2. What is your citizenship status?

| | | | | | | | |
|-----------------------|--|------------------------------------|--|-------------------|--|--------------------|--|
| British Citizen | | Refugee | | Migrant Worker EU | | Migrant worker A2 | |
| Non EU Migrant Worker | | Family Migrant-Permanent Residency | | Asylum Seeker | | Other please state | |

3. What language are you most comfortable speaking? Give one answer only

| | | | | |
|---------|--|--------|--|------------------|
| Czech | | Polish | | Roma |
| English | | Slovak | | Other (specify): |

4. What other languages do you speak well?

| | | | | |
|---------|--|--------|--|------------------|
| Czech | | Polish | | Roma |
| English | | Slovak | | Other (specify): |

5. How would you describe your spoken English?

| | | | | | | | |
|-------------|--|-----------|--|--------|--|-------------|--|
| Fluent/Well | | Well / OK | | Little | | None at all | |
|-------------|--|-----------|--|--------|--|-------------|--|

6. Do you or anyone in your household have any longstanding illness or disability?

(By longstanding we mean anything that has troubled you over a long period of time or that is likely to affect you over a period of time)

| | | | | | |
|-----|--|----|--|-------------|--|
| Yes | | No | | Not sure | |
|-----|--|----|--|-------------|--|

7. If yes are you/they registered disabled

| | | | | | | | |
|-----|--|----|--|------|--|----------|--|
| Yes | | No | | Some | | Not Sure | |
|-----|--|----|--|------|--|----------|--|

8. Does this/Do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life?

| | |
|--|--|
| Mobility (moving about) | |
| Lifting, carrying or moving objects | |
| Manual dexterity (using your hands to carry out everyday tasks) | |
| Continence (bladder and bowel control) | |
| Communication (speech, hearing or eyesight) | |
| Memory or ability to concentrate, learn or understand | |
| Recognising when you are in a physical danger | |
| Your physical co-ordination (e.g. balance) | |
| Other health problem or disability | |
| None of these | |

9. How many people in total, including yourself, currently live in your household?

Give number

10. How many children in your household are under 18?

Give number:

11. How many people in your household, including yourself, are over 65?

Give number:

12. Are you a carer?

(A carer is someone of any age who helps a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems, with personal things e.g. getting them dressed, turning them in their sleep, helping them to the toilet, helping them move about or giving their medication.)

| | | | |
|-----|--|----|--|
| Yes | | No | |
|-----|--|----|--|

About the area you live in**13. What do you feel is the biggest community problem in your area?**

| | Not included in original questionnaire |
|-----------------------------------|--|
| Crime in general | |
| Crime against Roma people | |
| Neighbours are not welcoming | |
| Housing is in poor condition | |
| Litter and rubbish on the streets | |
| Drugs | |
| Place for Roma people to meet | |
| Activities for young Roma people | |
| Other please give examples | |

14. Have you been a victim of crime or violence in the last year? If so what....**15. If yes did you report it and who to**

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not Sure | |
|-----|--|----|--|----------|--|

16. If yes do you think you were a victim because of you nationality?

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not Sure | |
|-----|--|----|--|----------|--|

17. Do you feel that you or someone in your family has faced prejudice or discrimination while you have been in the UK because you are Roma? This can include name calling, verbal and physical abuse, graffiti, poor or mistreatment or being excluded. Please give an example if possible.

18. If yes how often has this happened?

| | | | | | | | | | |
|-------|--|---|--|--|--|---|--|---|--|
| Never | | Hardly ever – maybe once in the last few months | | Occasionally – once or twice every few months | | Often – at least once a month or more | | All the time – almost every week or more | |
|-------|--|---|--|--|--|---|--|---|--|

About your health and use of health services

19. Are you registered with doctor

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not Sure | |
|-----|--|----|--|----------|--|

20. If yes, which post code is your doctor in?

21. If no why not, please state:

(e.g. don't know how to find GP, cannot be understood by receptionist, feel unwelcome, worried about change etc.)

22. Are you registered with a dentist?

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not Sure | |
|-----|--|----|--|----------|--|

23. If no why not please state:

(e.g. don't know how to find dentist, cannot be understood by receptionist, feel unwelcome, worried about change etc.)

24. Do you use your pharmacy (chemist) for : (tick all that apply)

| | |
|---|--|
| Prescription medicines (which your doctor has given) | |
| 'Over the counter' medicines like paracetamol or cold relief medicine | |
| General Health Advice | |
| Health Services e.g. blood pressure, giving up smoking, blood tests | |
| Other, please state | |

25. In general how do you feel most days?

| | | | | | |
|--------------------|--|-------|--|------------------|--|
| Happy | | OK | | Stressed/Anxious | |
| Low Mood/Feel down | | Angry | | Sad | |

26. Have any of the following below caused you stress in the past year? (Please tick all that apply)

| | | | | | | | |
|------------------------|--|-------------------|--|--|--|------------------|--|
| Not being able to work | | Family Life | | Relationships | | Money Problems | |
| Work Pressure | | Caring for Others | | Neighbourhood/Local area | | Feeling Isolated | |
| Lack of Money | | Religion | | Access to Training and Education Opportunities | | Other | |
| If other please state: | | | | | | | |

27. Has any stress resulted in conflict, arguments or violence in your family?

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not Sure | |
|-----|--|----|--|----------|--|

28. If you indicated in question 20 something that has caused you stress in the past year what do you think could help you to reduce this? (Please tick all that apply)

| | | | | | | | |
|--|--|---------------------------------------|--|---------------------------------|--|-------------------|--|
| Counselling | | More free time | | Information | | Physical Activity | |
| General Advice from a Professional (e.g. doctor, social worker, nurse) | | Money Advice or Benefits/Entitlements | | Support from Family and Friends | | Other | |
| If other, please state | | | | | | | |

29. Which of the following best describes you?

| | | | |
|-------------------------------|--|--------------------------------------|--|
| A non-smoker | | An ex-smoker | |
| A smoker who wants to give up | | A smoker who doesn't want to give up | |

30. If you are a smoker, how many cigarettes do you smoke per day?

| | | | | |
|----------------|------|-------|--------|------------|
| Less than 5 | 5-10 | 11-15 | 15-20+ | 20 or more |
|----------------|------|-------|--------|------------|

31. How many times do you have a drink containing alcohol?

| | | | | |
|-------|-----------------|--------------------------|-------------------------|----------------------|
| Never | Monthly or less | 2 - 4 times per month | 2 - 3 times per week | 4+ times per week |
|-------|-----------------|--------------------------|-------------------------|----------------------|

32. Do you know what constitutes 1 unit of alcohol?

| | | |
|-----|----|----------|
| Yes | No | Not Sure |
|-----|----|----------|

33. If yes, how many units do you drink per week?

| | | | | |
|---------|---------|---------|---------|-----|
| 1- 2 | 3- 4 | 5- 6 | 7- 9 | 10+ |
|---------|---------|---------|---------|-----|

34. On a scale of 1-5 how easy do you find it to get hold of fresh fruit and vegetables?

Very Easy

Very Hard

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

35. Yesterday, how many portions of fruit and vegetables did you eat?

(A portion is a piece of fruit or handful of small fruits such as grapes, a glass of fruit juice or a serving of vegetables. Please do not include potatoes.)

Please tick as appropriate:

| | | | |
|---|-----|-----|-----------|
| 0 | 1-2 | 3-4 | 5 or more |
|---|-----|-----|-----------|

36. How many days a week do you get 30 minutes of physical activity that makes your heart beat fast and gets you feeling slightly breathless?

(This activity can range from housework, gardening and walking to playing sport)

| | | | | | | | |
|---------|---|---|---|---|---|---|---|
| No days | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | | | | | | | |

37. When you or a member of your family fall ill and you want medical help or advice where are you most likely to go?

| | |
|------------------------------|--|
| Your pharmacist (chemist) | |
| NHS Direct | |
| Your GP (local doctor) | |
| Accident and Emergency (A&E) | |
| A drop-in health centre | |
| Religious Leader | |
| Friends or Family | |
| Other please state: | |

38. Where would you go if you were concerned about your Sexual Health?

| | | | | | |
|------------------|--|----------------------------|--|-------------------------------|--|
| Doctor/GP | | Local Sexual Health Clinic | | CaSH (Family Planning Clinic) | |
| Family/Friend | | Don't know | | Don't Use | |
| Religious Leader | | Other (please state) | | | |

39. Are you aware of the following services or immunisations? (Vaccination protects against infectious diseases that can be life-threatening.)

| Immunisation Service | Delivered by | |
|---|---|--|
| Childhood immunisation programme (given during 2 months – 18 years of age) | GP Practices | |
| Seasonal flu vaccination programme (given during September – end January) | GP Surgery | |
| Pneumococcal programme to protect against pneumonia (given to those aged 65 years and those in certain risk groups aged 2 years and over) | GP Surgery | |
| HP vaccination programme to protect against cervical cancer. (given during 12-13 years of age (year 8 at school)) | In school by the school immunisation team | |

40. Are you aware of the following screening programmes?
(Tick all that apply)

| | |
|--------------------------------|--|
| Abdominal screening | |
| Bowel screening | |
| Breast screening | |
| Cervical screening | |
| Diabetic retinopathy screening | |
| Anti-natal screening | |
| New born screening | |

41. Have you experienced any barriers while using the above services (immunisations and screenings)

42. Are you aware of the NHS Health Check with looks at heart health factors?

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not Sure | |
|-----|--|----|--|----------|--|

About your GP/Doctor

How do you feel about the service you receive from your doctor?

| | | | | |
|----------|------|----------------|------|-----------|
| ☹☹ | ☹ | ☺ | ☺ | ☺☺ |
| Very bad | poor | indifferent/OK | good | excellent |

43. Why you have given this score?

44. What are the good things about your doctor and their service, what do they do well?

45. What could your doctor and their service do better, how could they improve?

46. Is there anything else that makes it difficult to use your doctor and their service?

About hospital services

47. How often in the last 12 months have you used hospital services such as out patients (e.g. skin care), Accident and Emergency (A&E), pregnancy and baby services and in-patients (e.g. when you had an accident where you needed to stay in hospital)?

Please circle the appropriate number:

| | | | |
|---|-----|-----|-----------|
| 0 | 1-2 | 3-4 | 5 or more |
|---|-----|-----|-----------|

48. How do you feel about the service you receive from the hospital

| | | | | |
|----------|------|----------------|------|-----------|
| ☹☹ | ☹ | ☺ | ☺ | ☺☺ |
| Very bad | poor | indifferent/OK | good | excellent |

49. Can you explain why you have given this score?

50. What is your hospital doing well?

51. How could your hospital service be improved?

52. Is there anything else that makes it difficult to use your hospital service?

Language needs

53. Do you find language a problem when using health services?

(This can be in the form of written information or while communicating with health services staff)

| | | | | | | | |
|-------------------------|--|-----------|--|-------------|--|-------|--|
| Always/most of the time | | Sometimes | | Hardly ever | | Never | |
|-------------------------|--|-----------|--|-------------|--|-------|--|

54. If 'always/most of the time' or 'sometimes' who are you most likely to rely on for support when you use the health service?

| | | | | | |
|------------------------|--|--------------------|--|-------------|--|
| Family and Friends | | Bilingual Advocate | | Interpreter | |
| Telephone interpreting | | Others | | No-one | |

55. Do you have any other difficulties, concerns or worries when using health or social care services such as doctors, dentists, hospitals, health centres, children's centres, social workers etc.?

***In particular,
Even if an interpreter or telephone interpretation is used...***

56. Do you feel you understand the advice given to you

| | | | | | | |
|-------------------------|--|-----------|-------------|--|-------|--|
| Always/most of the time | | Sometimes | Hardly ever | | Never | |
|-------------------------|--|-----------|-------------|--|-------|--|

57. Do you feel able to ask questions or ask for more information?

| | | | | | | |
|-------------------------|--|-----------|-------------|--|-------|--|
| Always/most of the time | | Sometimes | Hardly ever | | Never | |
|-------------------------|--|-----------|-------------|--|-------|--|

58. Do you feel you have a say in the decisions made about you?

| | | | | | | |
|-------------------------|--|-----------|-------------|--|-------|--|
| Always/most of the time | | Sometimes | Hardly ever | | Never | |
|-------------------------|--|-----------|-------------|--|-------|--|

59. Do you feel you are treated with dignity and respect?

If not please say why

60. In your opinion what one thing could health services (hospitals/doctors) do differently, that would make the biggest difference to you, your family and the Roma communities?

61. This is an opportunity to pass a message on to those that plan the health services in Leeds

62. Has housing, schools, work, access to benefits etc. affected you or your family's health in a good or bad way (Please give examples)

Appendix 2: Shortened Survey



Advocacy Support
[Ltd]

The Roma Centre

Roma Health Needs Assessment

Advocacy Support, the Roma centre and NHS Leeds are working together to improve access to services and to improve the general health and well-being of the Leeds Roma community.

Everything you say will be treated in total confidence.

Your personal details will not be passed on to Leeds City council, NHS Leeds, GPs or any other organisation.

This survey cannot be used to affect any benefits or payments you may be receiving.

For office use:

Interviewer(s) name(s):

This survey is for members of the Roma community only

About you

| | | | | | | |
|---------|------|--|--------|--|-----------|--|
| Gender: | Male | | Female | | Post code | |
|---------|------|--|--------|--|-----------|--|

| | |
|---------------|--|
| Date of Birth | |
|---------------|--|

63. How would you describe your Roma community?

| | | | | |
|------|--|-------------|--|--------------|
| Roma | | Vlacho Roma | | Other state: |
|------|--|-------------|--|--------------|

64. What is your citizenship status?

| | | | | | | | |
|-----------------------|--|------------------------------------|--|-------------------|--|--------------------|--|
| British Citizen | | Refugee | | Migrant Worker EU | | Migrant worker A2 | |
| Non EU Migrant Worker | | Family Migrant-Permanent Residency | | Asylum Seeker | | Other please state | |

65. What language are you most comfortable speaking? Give one answer only

| | | | | |
|---------|--|--------|--|------------------|
| Czech | | Polish | | Roma |
| English | | Slovak | | Other (specify): |

66. What other languages do you speak well?

| | | | | |
|---------|--|--------|--|------------------|
| Czech | | Polish | | Roma |
| English | | Slovak | | Other (specify): |

67. How would you describe your spoken English?

| | | | | | | | |
|-------------|--|-----------|--|--------|--|-------------|--|
| Fluent/Well | | Well / OK | | Little | | None at all | |
|-------------|--|-----------|--|--------|--|-------------|--|

68. Do you or anyone in your household have any longstanding illness or disability?

(By longstanding we mean anything that has troubled you over a long period of time or that is likely to affect you over a period of time)

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not sure | |
|-----|--|----|--|----------|--|

69. If yes are you/they registered disabled

| | | | | | | | |
|-----|--|----|--|------|--|----------|--|
| Yes | | No | | Some | | Not Sure | |
|-----|--|----|--|------|--|----------|--|

70. How many people in total, including yourself, currently live in your household?

Give number

71. How many children in your household are under 18?

Give number:

72. How many people in your household, including yourself, are over 65?

Give number:

73. Are you a carer?

(A carer is someone of any age who helps a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems, with personal things e.g. getting them dressed, turning them in their sleep, helping them to the toilet, helping them move about or giving their medication.)

| | | | |
|-----|--|----|--|
| Yes | | No | |
|-----|--|----|--|

About the area you live in

74. What do you feel is the biggest community problem in your area?

| | |
|-----------------------------------|--|
| Crime in general | |
| Crime against Roma people | |
| Neighbours are not welcoming | |
| Housing is in poor condition | |
| Litter and rubbish on the streets | |
| Drugs | |
| Place for Roma people to meet | |
| Activities for young Roma people | |

| | |
|-----------------------------------|--|
| Other please give examples | |
|-----------------------------------|--|

About your health and use of health services

75. Are you registered with doctor

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not Sure | |
|-----|--|----|--|----------|--|

76. If yes, which post code is your doctor in?

77. If no why not, please state:

(e.g. don't know how to find GP, cannot be understood by receptionist, feel unwelcome, worried about change etc.)

78. Are you registered with a dentist?

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not Sure | |
|-----|--|----|--|----------|--|

79. If no why not please state:

(e.g. don't know how to find dentist, cannot be understood by receptionist, feel unwelcome, worried about change etc.)

80. In general how do you feel most days?

| | | | | | |
|--------------------|--|-------|--|------------------|--|
| Happy | | OK | | Stressed/Anxious | |
| Low Mood/Feel down | | Angry | | Sad | |

81. Have any of the following below caused you stress in the past year? (Please tick all that apply)

| | | | | | | | |
|------------------------|--|-------------------|--|--------------------------|--|------------------|--|
| Not being able to work | | Family Life | | Relationships | | Money Problems | |
| Work Pressure | | Caring for Others | | Neighbourhood/Local area | | Feeling Isolated | |

| | | | | | | | |
|------------------------|--|----------|--|--|--|-------|--|
| Lack of Money | | Religion | | Access to Training and Education Opportunities | | Other | |
| If other please state: | | | | | | | |

82. Has any stress resulted in conflict, arguments or violence in your family?

| | | | | | |
|-----|--|----|--|----------|--|
| Yes | | No | | Not Sure | |
|-----|--|----|--|----------|--|

83. If you indicated in question 20 something that has caused you stress in the past year what do you think could help you to reduce this? (Please tick all that apply)

| | | | | | | | |
|--|--|---------------------------------------|--|---------------------------------|--|-------------------|--|
| Counselling | | More free time | | Information | | Physical Activity | |
| General Advice from a Professional (e.g. doctor, social worker, nurse) | | Money Advice or Benefits/Entitlements | | Support from Family and Friends | | Other | |
| If other, please state | | | | | | | |

84. Which of the following best describes you?

| | | | |
|-------------------------------|--|--------------------------------------|--|
| A non-smoker | | An ex-smoker | |
| A smoker who wants to give up | | A smoker who doesn't want to give up | |

85. If you are a smoker, how many cigarettes do you smoke per day?

| | | | | | | | | | |
|-------------|--|------|--|-------|--|--------|--|------------|--|
| Less than 5 | | 5-10 | | 11-15 | | 15-20+ | | 20 or more | |
|-------------|--|------|--|-------|--|--------|--|------------|--|

86. How many times do you have a drink containing alcohol?

| | | | | | | | | | |
|-------|--|-----------------|--|-----------------------|--|----------------------|--|-------------------|--|
| Never | | Monthly or less | | 2 - 4 times per month | | 2 - 3 times per week | | 4+ times per week | |
|-------|--|-----------------|--|-----------------------|--|----------------------|--|-------------------|--|

87. On a scale of 1-5 how easy do you find it to get hold of fresh fruit and vegetables?

Very Easy

Very Hard

| | | | | | | | | | |
|---|--|---|--|---|--|---|--|---|--|
| 1 | | 2 | | 3 | | 4 | | 5 | |
|---|--|---|--|---|--|---|--|---|--|

88. Yesterday, how many portions of fruit and vegetables did you eat?

(A portion is a piece of fruit or handful of small fruits such as grapes, a glass of fruit juice or a serving of vegetables. Please do not include potatoes.)

Please tick as appropriate:

| | | | | | | | |
|---|--|-----|--|-----|--|-----------|--|
| 0 | | 1-2 | | 3-4 | | 5 or more | |
|---|--|-----|--|-----|--|-----------|--|

89. How many days a week do you get 30 minutes of physical activity that makes your heart beat fast and gets you feeling slightly breathless?

(This activity can range from housework, gardening and walking to playing sport)

| | | | | | | | |
|---------|---|---|---|---|---|---|---|
| No days | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| | | | | | | | |

90. When you or a member of your family fall ill and you want medical help or advice where are you most likely to go?

| | |
|------------------------------|--|
| Your pharmacist (chemist) | |
| NHS Direct | |
| Your GP (local doctor) | |
| Accident and Emergency (A&E) | |
| A drop-in health centre | |
| Religious Leader | |
| Friends or Family | |
| Other please state: | |

About your

How do you feel about the service you receive from your doctor?

GP/Doctor

| | | | | |
|----------|------|----------------|------|-----------|
| ☹☹ | ☹ | ☺ | ☺ | ☺☺ |
| Very bad | poor | indifferent/OK | good | excellent |

91. Why you have given this score?

92. What could your doctor and their service do better, how could they improve?

About hospital services

93. How often in the last 12 months have you used hospital services such as out patients (e.g. skin care), Accident and Emergency (A&E), pregnancy and baby services and in-patients (e.g. when you had an accident where you needed to stay in hospital)?

Please circle the appropriate number:

| | | | |
|---|-----|-----|-----------|
| 0 | 1-2 | 3-4 | 5 or more |
|---|-----|-----|-----------|

94. How do you feel about the service you receive from the hospital

| | | | | |
|----------|------|----------------|------|-----------|
| ☹☹ | ☹ | ☺ | ☺ | ☺☺ |
| Very bad | poor | indifferent/OK | good | excellent |

95. Can you explain why you have given this score?

96. How could your hospital service be improved?

Language needs

97. Do you find language a problem when using health services?

(This can be in the form of written information or while communicating with health services staff)

| | | | | | | | |
|-------------------------|--|-----------|--|-------------|--|-------|--|
| Always/most of the time | | Sometimes | | Hardly ever | | Never | |
|-------------------------|--|-----------|--|-------------|--|-------|--|

98. If 'always/most of the time' or 'sometimes' who are you most likely to rely on for support when you use the health service?

| | | | | | |
|------------------------|--|--------------------|--|-------------|--|
| Family and Friends | | Bilingual Advocate | | Interpreter | |
| Telephone interpreting | | Others | | No-one | |

In particular,

Even if an interpreter or telephone interpretation is used...

99. Do you feel you understand the advice given to you

| | | | | | | | |
|-------------------------|--|-----------|--|-------------|--|-------|--|
| Always/most of the time | | Sometimes | | Hardly ever | | Never | |
|-------------------------|--|-----------|--|-------------|--|-------|--|

100. Do you feel able to ask questions or ask for more information?

| | | | | | | | |
|-------------------------|--|-----------|--|-------------|--|-------|--|
| Always/most of the time | | Sometimes | | Hardly ever | | Never | |
|-------------------------|--|-----------|--|-------------|--|-------|--|

101. Do you feel you have a say in the decisions made about you?

| | | | | | | | |
|-------------------------|--|-----------|--|-------------|--|-------|--|
| Always/most of the time | | Sometimes | | Hardly ever | | Never | |
|-------------------------|--|-----------|--|-------------|--|-------|--|

102. Is there anything else you would like to tell us about health services in Leeds?

THIS SHEET WILL BE SEPARATED FROM YOUR SURVEY ANSWERS

To make sure we are doing our job properly, we will telephone a number of people interviewed and ask them to confirm that an interview has taken place. Can we please take some details so this can be checked?

Name:

Telephone number

Preferred language:

Thank you for completing our survey.
If you would like any further information or support with any of the issues or difficulties raised by the questions above please come to a drop-in session or ring for an appointment.

Advocacy Support 0113 235 1877
Free support in your language

Drop-ins are every Tuesday, Wednesday and Thursday 10am – 12 noon
267 Roundhay Road, Leeds LS8 4HS

Appendix 3: Focus Group Questions

Focus Group: GPs/ Hospitals GUIDE QUESTIONS

Introduction & Set-Up

- Introduce the researchers
- Ask participants to introduce their name

Focus Group Guide Questions:

General: intro:

Introduce today's theme

GPs and hospitals

I have a series of questions I will ask you – all of which relate to your opinions and experiences – so there are no right or wrong answers. The questions cover your experience of using GPs and hospitals

- **We will not make judgments about what you have done or your experience.**
- **What you say today cannot have an adverse effect on the service you get receive; your names will not be used.**

Warm up:

In Pairs: ask the group to talk the person next to them about the last trip to the GP / hospital.

We hoping to give everyone the chance to talk about their experiences and say all the things they've just begun speaking about and more.

- 1) **How often have you used your GP in the last 12 months** say some of the things you went for?
Go round all or most to answer - Notes on which services which part of hospital e.g. out patients, A&E, minor injuries centre, walk-in,
- 2) **Those who had an appointment** – *discuss first GPs then hospitals*
Separate notes into GPs and Hospitals
 - a) how easy was it to get
 - b) Did you have to wait to get an appointment; *-was it acceptable, very quick too long how did you feel about that?*
 - c) Was the time good for you
Ease of making appointment -describe what was helpful and what made it difficult
Did you feel you were treated with respect?
Does this reflect what your family and friends feel?
3. **Drop in surgery: GPs or A&E, walk-in centres, minor injury centres?**
 - a) how easy was it to get to *describe what was helpful and what made it difficult*
 - b) Did you have to wait to get an appointment; *-was it acceptable, very quick too long how did you feel about that?*
 - c) Was the time good for you

d) Ease of booking in at reception -*describe what was helpful and what made it difficult*

Did you feel you were treated with respect?

Once you were being treated...

- a) Was an interpreter offered –*did you feel you wanted one*
- b) how well did you communicate –i.e. interpreter, family member friend, make do in English scale 1 very poor – 5 excellent
- c) Did you get the treatment you expected – *what did you expect, was the difference good or bad?*
- d) Did they explain everything they were doing?
- e) Did you feel able to ask questions?

- f) Were you given the information you wanted and could you understand it?

- g) Do you feel your opinions were taken into account, ...why explain

- h) Did the doctor or health worker treat you with respect?

4. Is there anything else you would like to say about your health service?

Are there any questions you were expecting or hoping to be asked?

Is there anything that is particularly good or bad about your experience with health services in Leeds?

Any message you want to give to GPs or the hospitals?

Focus Group: Healthy Lifestyles GUIDE QUESTIONS

Focus Group Guide Questions:

General: intro:

Introduce today's theme
 Healthy Lifestyles
 Standard Introduction

Pairs: what things do you do that contribute to keeping you healthy what things do you do that are not good for your health?

1. On a score of 1 -5, 1 being very unhealthy 5 is very healthy how healthy do you rate your life style.

Go round

2. What are the things that we should all be doing to keep ourselves healthy?

Note range and depth of understanding
 Probe for food types, levels of exercise, levels of use of alcohol/ smoking other drugs etc.

3. What is 'good health'

What are the signs of a healthy person –question if there are emotional factors if necessary

4. What helps you to eat healthily and what stops you from being able to do this?

Probe: Influence of culture,
 Time to shop,
 Ease of access to affordable food,
 Reaffirm understanding of what is healthy (bad example) e.g. is a big Mac considered healthy if it has a slice of tomato in it.
 Describe typical meals in any given week

5. Do they feel that reflects the what is typical for the wider Roma community

6. What would help you have a healthier diet?

Get both general suggests and practical action for them as individuals /families.

Possible suggestions: shops that sell particular types of food; cheaper fresh fruit and veg; knowing how to cook some things? Etc.

7. Is Physical activity important to you? And are you able to exercise regularly?

What types of exercise do they get?
 Are they often out of breath and how much activity gets them out of breath?

8. What helps you and what prevents you from Physical activity?

Probe: role of lack of motivation; facilities available; cultural / faith factors e.g. women only space, expectations, age appropriate

9. What would help you to get more PA

Probe: help with motivation; facilities available; cultural / faith factors e.g. women only space, expectations, age appropriate

Alcohol and Smoking and other drugs

10. How much do people here smoke or drink?

11. Is that typical for the wider community?

-Our survey showed a high number of smokers but a low number of drinkers does that seem accurate?

12. What contributes to the reasons why people smoke and drink as much / as little as they do?

Stress caused by...

Peer pressure –everyone does

Etc.

Separate answers for drinking and smoking

13. Is drug use common within the community?

Which ones

Affect certain ages, genders etc.

Does it cause problems health or otherwise

14. Do you know where you could get support to stop if you wanted to?

15. Do you think that support is effective?

Overall Health

16. What do you think are the 3 things that have the worst impact on your health?

17. What 3 things would make the biggest difference to improving your health?

18. If you want to make changes would you know where to go to get health support if you need it?

19. What services have you used and what was your experience?

20. What else could/would help?

21. If we are able to get some general health campaign materials use a) If we can't use b)

a) Have you seen any of the leaflets/ information and do you know what they are about?

b) Have you seen any information or adverts or leaflets telling you where you can help to stop smoking, exercise more, keep your heart healthy generally stay healthy?

What were they for?

How useful were they

22. Is there any way the NHS can improve how they tell you about the support available?

Leaflet in languages

Are radio ads better than TV?

What would make participants more likely to go to a 'health awareness day'?

How can NHS give information to all the Roma community?

23. Do you have anything else you want to say to the Health service or the council?

Focus Group: Income and employment GUIDE QUESTIONS

Focus Group Guide Questions:

General: intro:

Introduce today's theme

Income and employment

Income and unemployment guide questions

Standard Introduction emphasis very sensitive information

Pairs:

1 **On a score of 1 -5, how easily are you able to pay all your bills?**

| 1 | 2 | 3 | 4 | 5 |
|--|--|--|---|---|
| Can never pay them all – always have some debts | hard to pay bills sometimes fall behind | Just manage to keep them all paid | Able to pay them all without worry | Pay them easily so never think about the bills |

Go round

2 **Are you ever faced with a large unexpected bill or expenses (car repair, new cooker etc. how do you usually respond to it?**

E.g.: borrow money from family / friends

Borrow from bank, lender (where from)

Cut back on other things

Ignore it

Other?

3 **When/ if you try to cut back on how much you're spending each week, which things are you most likely to go without?**

Or what changes are you most likely to make.

Would you change the type of food you buy, where you buy it etc.?

Does anyone smoke/drink? – is it easy to cut back?

Which things would you not cut back on?

4 **Do they feel that reflects the what is typical for the wider Roma community In the winter how easy is it to keep your home warm?**

Have you noticed if any of this, e.g. the cutting back to pay bills, not heating the home properly etc. (use examples from what has been said) has an effect on your health and your families health?

Get examples

Ask about stress, general feeling well and happy, illness e.g. colds, chest infections, asthma etc.

5 **Have you ever checked that you are getting all the benefits and entitlements you are eligible for, even if you are working?**

How

Where would you go to do it?

6 Have you ever compared electricity and gas company prices to see if yours is the cheapest you can get?

How?

Where would you go to do it?

How do you pay your gas and electric bills e.g. meter, card DD etc.

7 Have you ever spoken to a money expert or debt adviser or for help in managing your money?

Where did you go?

What other places could you go to?

Would you think of going to CAB, national free debt help services such as national debt help line, CCCS?

8 How easy was it to use the service / would anything put you off from using a money expert or debt adviser

How about when applying for benefits or housing etc. how easy is it to use those services?

Does anything put you off?

Are you always offered an interpreter?

Do you feel that everything was explained properly?

That you understood everything?

Did you feel you could ask questions if something was not clear?

How could those services be improved?

Employment

What is it like looking for a job when you are Roma?

Is there a type of job most Roma people Leeds tend to go for?

Is it different between men and women, age?

Does speaking English help? How much?

How useful are places like job centre plus?

Connexions for young people?

Check if interpreters are used.

What could be done to make finding a job easier?

Do you know where to get help with a CV?

Do you know where to find out how getting a part time job may affect your benefits?

Is there any other support in finding work or increasing your income?

Do you have anything else you want to say to the Health service or the council?

Appendix 4: Interview Guide Sheet

- 1) What is the nature of your work/involvement with the Roma community?
- 2) What do you see as the biggest need of the Roma community/communities in Leeds? (Probe further, depending on answer, e.g. ask about language, employment, benefit, discrimination, safety etc.)
- 3) What is the biggest obstacle/challenge that you face in your work?
- 4) Do you think that the Roma face discrimination here in Leeds? (probe further – have you been to CZ/SK – do you think they face discrimination there, why do you think they come here)
- 5) What services are there for the Roma community in Leeds?
- 6) How does the current economic climate and cuts impact on the service you provide to the Roma community? What impact does that have on the Roma themselves? (probe further about impacts on health of Roma)