



# Talk, Listen, Change (TLC)

engaging in a dialogue with the Luton Roma community on access to healthcare services and co-producing solutions

## PROJECT REPORT

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## **Acknowledgments**

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## 1.0 BACKGROUND

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One of the largest concentrations of the Roma community is in Luton, Europe.<sup>1</sup> The Roma community come from all over Eastern Europe, from countries such as Romania, Bulgaria, the Czech Republic, and Slovakia. The Luton Roma Trust is a charity (charity no. 1202863) which was formed in 2015 and provides a wide range of free services to the Luton Roma community supporting and facilitating their integration into wider society whilst maintaining their cultural values.<sup>2</sup> Responding to the Roma community needs, the Luton Roma Trust has identified that access to healthcare remains one of the main challenges facing the Roma community in Luton. The Luton Roma Trust have identified some barriers to accessing healthcare as language and communication, low levels of digital literacy, and discrimination. A recent evaluation carried out by the Luton Roma Trust shows that the Roma community mistrust authorities and face multiple barriers to accessing healthcare services. This is evidenced by the fact that over 96% of the Roma living in Luton are not vaccinated.<sup>3</sup> The existing evidence base highlights that there are gaps in cultural competence and knowledge regarding the Roma community in the UK, which can leave gaps in the provision of services with negative effects on health.<sup>4</sup>

Given the vulnerabilities of this particular community, the Luton Roma Trust commissioned the Institute for Health Research (IHR) to engage in a dialogue with the Roma community on access to healthcare services and co-producing solutions. There is a dearth of literature in the UK that sets out how best to engage with the Roma community and give voice to their needs. This report presents evidence gathered from focus group discussions with the Roma community and interview data with professionals working with them. To the best of our knowledge, this is the first study exploring access to healthcare services with the Luton Roma community. Moreover, there is a dearth of literature in the UK that sets out how best to engage with the Roma community and give voice to their needs. Evidence from the project provides in-depth

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<sup>1</sup><https://smp.eelga.gov.uk/migrant-workers/parallel-lives-roma-project/the-roma-community-in-the-east-of-england/>

<sup>2</sup><https://lutonromatrust.org.uk/>

<sup>3</sup><https://lutonromatrust.org.uk/2022/05/20/evaluation-of-services/>

<sup>4</sup> Greenfields, M. (2017). Good practice in working with Gypsy, Traveller and Roma communities. *Primary Health Care*, 27(10), 24-29.

contextualised findings and co-produced solutions to ensure services meet the needs of the Luton Roma community.

## 2.0 THE COMMUNITY ENGAGEMENT PLAN

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### **Aim**

To engage in a dialogue with the Luton Roma community and professionals who work with them, to better understand their views on accessing healthcare services, and to co-develop solutions.

### **Objectives**

- To discuss and explore the Luton Roma community's views on the barriers and enablers to accessing healthcare services in Luton;
- To ascertain the perspectives of professionals who work with the Luton Roma community;
- To better understand how to work with the Luton Roma community to co-develop shared approaches to community healthcare priorities.

### 2.1 Approach

Researchers have recorded the challenge of engaging the Roma people in research (Condon, 2019). We used our Talk, Listen, Change (TLC) approach and worked in collaboration with the Luton Roma Trust to recruit and train community researchers. These trusted 'insiders' produced in-depth qualitative findings that prioritise voice and privilege lived experience to understand the barriers and solutions to accessing healthcare services in Luton. Therefore our research also provides methodological insights on the value of engaging with communities for making organisational change.<sup>5 6</sup>

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<sup>5</sup>[https://m.luton.gov.uk/Page/Show/Health\\_and\\_social\\_care/coronavirus/Pages/talk-listen-change-executive-summary.aspx#:~:text=The%20aim%20of%20the%20Talk,inequality%20and%20building%20solutions%20together.](https://m.luton.gov.uk/Page/Show/Health_and_social_care/coronavirus/Pages/talk-listen-change-executive-summary.aspx#:~:text=The%20aim%20of%20the%20Talk,inequality%20and%20building%20solutions%20together.)

<sup>6</sup>In 2020 the Institute for Health Research (IHR) was commissioned by Luton Borough Council to carry out a Talk, Listen Change (TLC) community engagement project to explore reasons for the disproportionate impact of COVID-19 on the Black, Asian, Minority Ethnic population (BAME) which was a response to the report on inequalities by Public Health England [https://assets.publishing.service.gov.uk/media/5f328354d3bf7f1b12a7023a/Disparities\\_in\\_the\\_risk\\_and\\_outcomes\\_of\\_COVID\\_August\\_2020\\_update.pdf](https://assets.publishing.service.gov.uk/media/5f328354d3bf7f1b12a7023a/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf) and Luton Council set an action plan to understand the reasons for the disproportionate impact of COVID-19 on BAME groups and address health inequalities. Within this plan there is a broad action to: "work with communities to better understand their needs and co-develop solutions to ensure services meet the needs of the Luton BAME population".

The TLC approach ensures we represent ethnic, age, gender, linguistic, national and social class differences, while including the lesser heard voices. The 'Roma people' or 'Roma community' refers to many sub-groups of people from across Central and Eastern Europe whose self-identity is determined by history and language.<sup>7</sup> The self-identity of the Roma community has been homogenised<sup>8</sup> usually for official census categorisation. The Roma people are communities within communities, and many of these communities are less visible in local and national data, because they do not self-identify with the Office of National Statistics (ONS) ethnic categories which conflates these histories under Gypsies, Roma and Travellers.

<https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity>

Consequently, we were as specific as possible when engaging with the Roma community, recognising ethno-national, religious and linguistic communities to avoid generalising or homogenising experience. Our approach captured people who have poor English language fluency or are unlikely to engage due to cultural and/or religious reasons, giving them the opportunity to influence decisions to tackle inequalities, provide access to healthcare knowledge, prevention knowledge and build trust. We acknowledged the growing number of Roma community members living in Luton [https://m.luton.gov.uk/Page/Show/Community\\_and\\_living/Luton%20observatory%20census%20statistics%20and%20mapping/population/Pages/2021-Census-population-figures.aspx](https://m.luton.gov.uk/Page/Show/Community_and_living/Luton%20observatory%20census%20statistics%20and%20mapping/population/Pages/2021-Census-population-figures.aspx) based on the Office of National Statistics (ONS) ethnic categories, <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity> but also recruited based on self-ascribed identity e.g. individuals who identify as Roma.

### 2.1.1 Inviting participants

A purposive<sup>9</sup> approach was used to invite the Roma community to participate in the focus group discussions and also professionals who work with them for the interviews.

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<sup>7</sup> We have used the descriptors of 'Roma people' and 'Roma community' interchangeably in this report. 'Roma people' describes the Roma as an ethnic group (common language, culture, heritage) while 'Roma community' refers to a group of people sharing similar characteristics including views, opinions, experiences and shared interests connected by where they live i.e. Luton.

<sup>8</sup> Csepe, György, and Dávid Simon. "Construction of Roma identity in Eastern and Central Europe: perception and self-identification." *Journal of Ethnic and Migration Studies* 30, no. 1 (2004): 129-150. Greenfield, M. (2017). Good practice in working with Gypsy, Traveller and Roma communities. *Primary Health Care*, 27(10), 24-29.

<sup>9</sup> Purposive approach refers to prospective participants being selected based on the particular objectives (or purpose) of the study. The characteristic of the sample should enable the objectives of



The Luton Roma Trust provided essential support to identify a suitable bilingual Roma community researcher to recruit and facilitate the focus group discussion, which meant we were able to remove cultural, linguistic, and religious barriers, and ascertain the lived experiences and opinions of the ‘lesser heard voices’. They also provided access to participants through their community links and identified professionals who worked with the Roma community for the interviews.

We modified and tailored our TLC branding to develop publicity materials to help recruit, engage the community, strengthen participation and gain trust around the project.



### 2.1.2 Conducting the focus group discussions and interviews

The focus group discussions and interviews were carried out using a semi-structured discussion guide.<sup>10</sup>

- 11 focus group discussions, totalling 64 participants from the Roma community.
- 9 interviews with professionals working with the Roma community.

The discussion guide for the Roma community covered the following broad themes:

- Knowledge about healthcare services in Luton.

the study to be met see Ritchie, J., Lewis, J., Nicholls, C.M. and Ormston, R. eds., 2013. *Qualitative research practice: A guide for social science students and researchers*. sage.

<sup>10</sup>The discussion guides for the focus groups with the Roma community and interviews with people who work with them are available on request from nasreen.ali@beds.ac.uk



- Experiences of using healthcare services in Luton: what has helped them to access and have a good experience, the challenges, and the bad experiences of healthcare services in Luton.
- Improving access and good experiences, and reducing the challenges and bad experiences of healthcare services for Roma people in Luton.

The discussion guide for the professionals who worked with the Roma community covered the following broad themes:

- Professionals background.
- Views about the Roma community healthcare priorities/concerns.
- Views about the experiences of the Roma people using healthcare services in Luton: what has helped them to access/and have a good experience and the challenges and bad experiences of healthcare services in Luton.
- Improving access and good experiences, and reducing the challenges and bad experiences of healthcare services for Roma people in Luton.

With permission, the focus group discussions were audio recorded, translated and transcribed by a bilingual researcher who spoke Romanian.<sup>11</sup> The interviews were carried out in English and transcribed by a Institute for Health Research (IHR) researcher. All researchers, translators and transcribers underwent appropriate research training.

Data collection was completed between June-September 2023. The focus group discussions with the Roma community took place at the Luton Roma Trust premises, and the interviews with professionals were carried out face-to-face or online.

### 2.1.3 Analysis

A thematic Framework Analysis approach was used to analyse the data.<sup>12</sup> This involved a detailed familiarisation of the data, identification of the key themes to form a coding frame, indexing the material according to the coding frame, and interpreting the findings in the context of research and policy and practice considerations. Based on previous successful research the numbers of focus group discussions and interviews we carried out were sufficient to generate adequate thematic depth and

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<sup>11</sup> We have presented verbatim quotes from the focus group discussions and interviews. We have selected as many quotes as possible that were relevant to the coding framework to enable voice and deepen understanding of the issues affecting the Roma community accessing healthcare services in Luton. To enhance readability of the quotes we have where necessary annotated quotes with square brackets to show modifications we have made to ensure the quotes reflect meaning.

<sup>12</sup> Ritchie, Jane, Liz Spencer, and William O'Connor. "Carrying out qualitative analysis." *Qualitative research practice: A guide for social science students and researchers* 2003 (2003): 219-62.

meet the objectives of this study. Nasreen Ali and Fiona Mackay carried out the analysis and 10% of the transcripts were re-coded by Gurch Randhawa to guarantee a degree of inter-rater reliability and transparency until a consensus on themes and sub-themes was reached.

Our participants were from a range of gender and age backgrounds and some were working. The size of our sample was small but we reached saturation<sup>13</sup> and the views of our participants may not be representative of all Roma people in Luton. The sample of professionals that work with the Luton Roma community provided a service provider perspective, which was essential for developing a framework for improving access to healthcare within the Roma community.

## 2.2 Ethical issues

All participation in the study was voluntary. The TLC community researchers gave potential participants an information sheet and obtained their verbal or written consent (by email) to be contacted to take part in a focus group or an interview. A consent form was signed before a focus group discussion or interview commenced. All participants were given a minimum of one week to read the information sheet and think about it, before taking part in the project. All participants were given a de-brief sheet signposting them to support helplines.

All data was treated as confidential and stored securely at the University of Bedfordshire. Recordings and transcripts of focus group discussions and interviews were anonymised. We ensured no person taking part in the project was identifiable by their name or location data (IP addresses, postcodes). We obtained ethics approval from the Institute for Health Research Ethics Committee (IHREC).

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<sup>13</sup> The principle of saturation in qualitative research is when the same themes repeat themselves. In other words no new information is emerging from discussions. See Ritchie, J., Lewis, J., Nicholls, C.M. and Ormston, R. eds., 2013. *Qualitative research practice: A guide for social science students and researchers*. Sage.

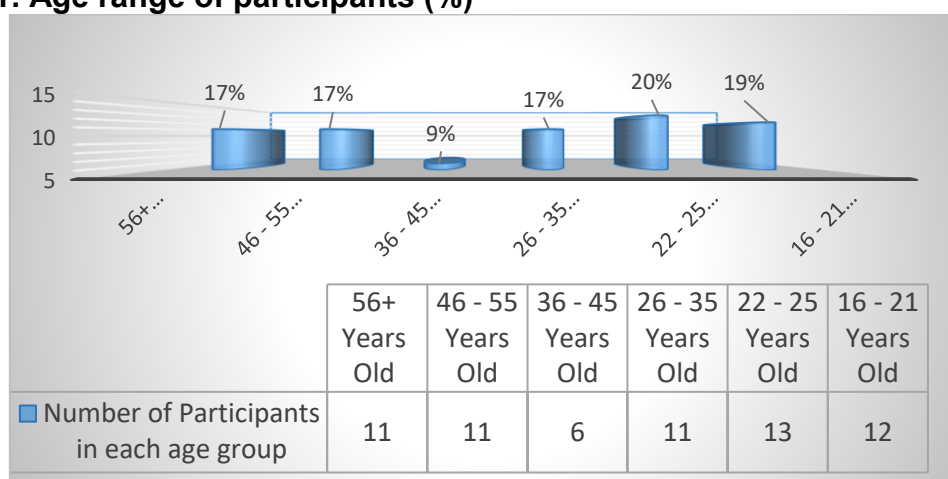
### 3.0 THE FINDINGS

The views from the focus group discussions with the Roma community, and interviews with professionals who work with them, are presented thematically in the sections below.

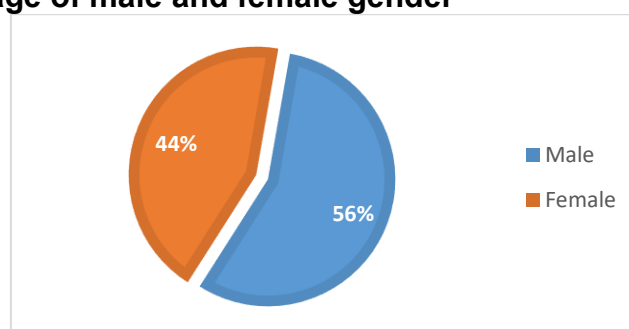
#### 3.1 Characteristics of the Roma focus group discussion participants

Eleven focus groups were conducted within the Roma community of Luton, and participants came from different age groups and genders. In total, 64 participants, aged between 16 and 62, participated in a focus group, with a mean age of 35.83 (SD = 14.7) (Figure 1). Most participants in the focus groups were male ( $n = 36$ ; 56%) (Figure 2).

**Figure 1: Age range of participants (%)**



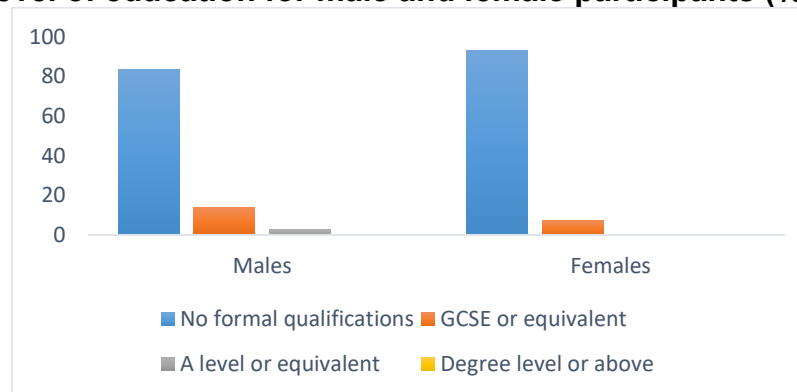
**Figure: 2 Percentage of male and female gender**



All participants were of Roma ethnicity and identified their religion as Christianity. Almost all participants ( $n = 63$ ; 98.4%) identified their main spoken language as Romanian, with one participant stating English (1.6%).

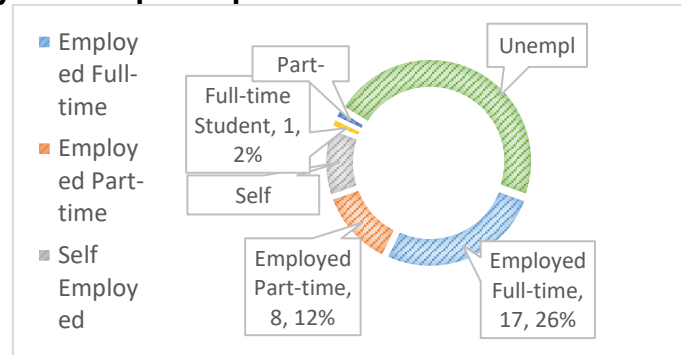
Most females who participated in a focus group had no formal qualification ( $n = 26$ ; 92.9%). A total of 7.1% ( $n = 2$ ) revealed that they had an education level of GCSE or equivalent, and none had an education level of A level or above. In relation to males, the majority also stated that they had no formal qualifications ( $n = 30$ ; 83.3%) qualifications. However, slightly more had GCSE or equivalent ( $n = 5$ ; 13.9%). One participant had A-levels (2.8%), and no one had a higher degree qualification (Figure 3).

**Figure: 3 Level of education for male and female participants (%)**

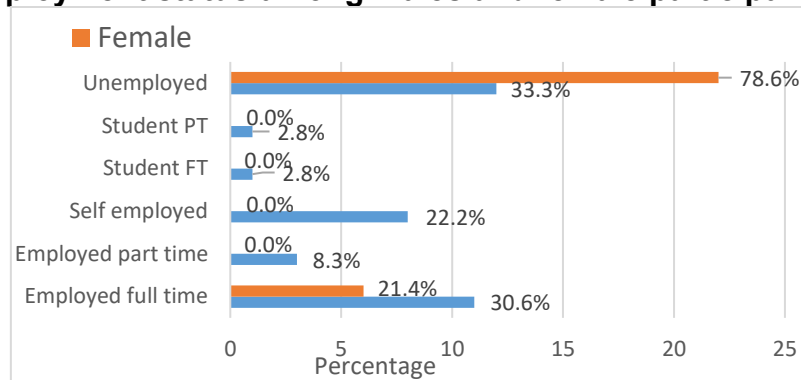


The participants were asked about their current occupation status and what job they were currently doing. Almost half of the participants were unemployed, 38% were part-time or full-time, and 9.4% were self-employed. Participants in full-time employment provided details of the types of job roles they were in; these included factory workers/warehouse operators ( $n = 6$ ; 12%), labourers ( $n = 4$ ; 24%), sales ( $n = 2$ ; 12%), construction operative ( $n = 3$ ; 18%), supervisor ( $n = 1$ ; 6%) and scrap workers ( $n = 2$ ; 12%). The remaining participants were either in part-time or full-time education (3%) (Figure 4). There were gender differences noted in relation to the participant's employment status. Females were more likely not to be employed, while males were more likely to be employed full or part-time or self-employed (Figure 5).

**Figure 4: Employment in participants**



**Figure 5: Employment status among males and female participants**

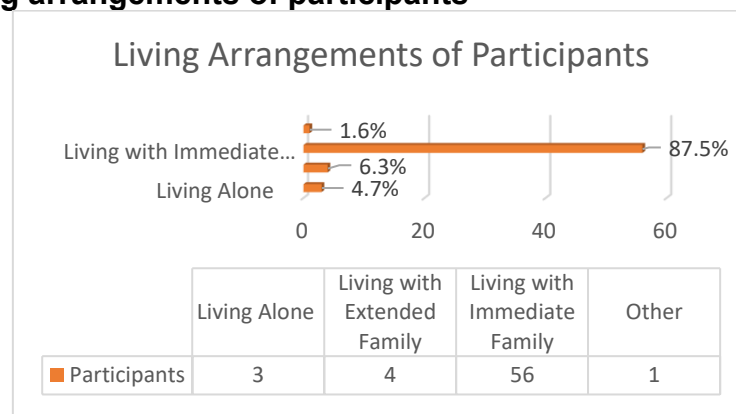


\*Employed full time= 35+hours per week

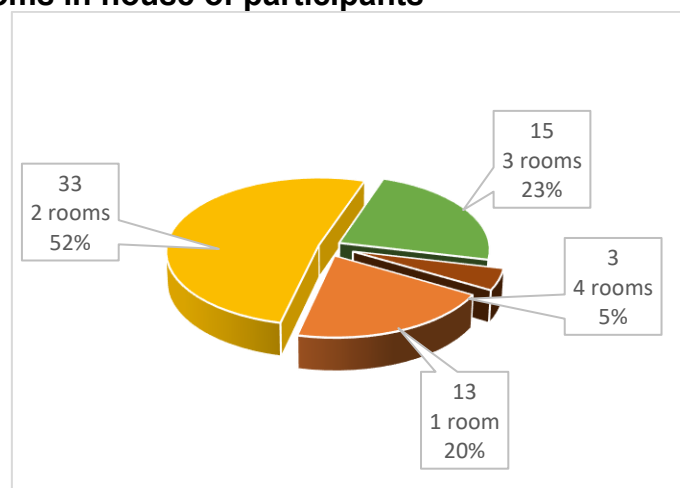
\*Part time employed= less than 35 hours per week

Among all the participants, the majority (n = 56; 87.5%) were living with immediate family, four participants (6.3%) were living with extended family, three (4.7%) were living alone, and one (1.6%) declared they had another living arrangement. Around half of the participants (52%) lived in a house with two bedrooms, 23% had three bedrooms, 20% had one bedroom, and the remaining 5% had four bedrooms or more (Figure 6).

**Figure 6: Living arrangements of participants**

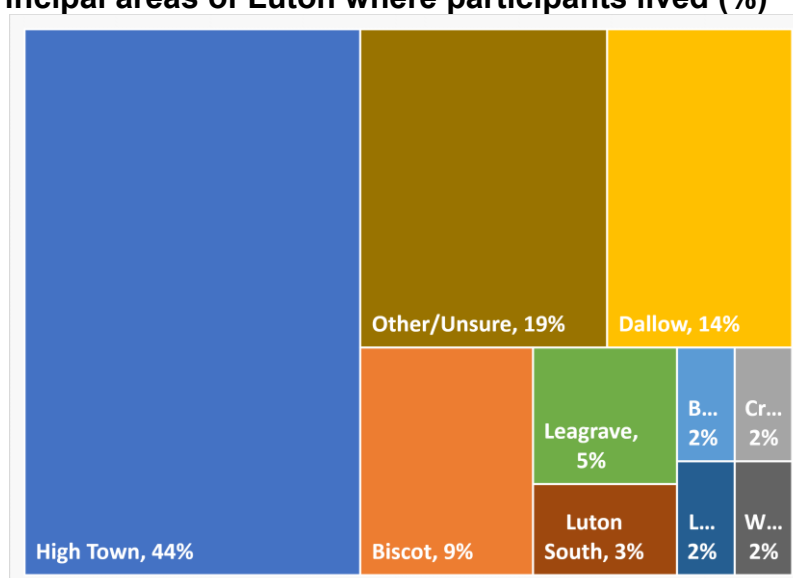


**Figure 7: Bedrooms in house of participants**



All participants resided in Luton, but the majority lived in High Town and the Dallow ward. Around twenty per cent stated that they were other/unsure, possibly due to an unsettled status (Figure 8).

**Figure 8: Principal areas of Luton where participants lived (%)**



### 3.2 Characteristics of the professionals who work with the Roma community

Nine interviews were carried out with professionals who work with the Luton Roma community from Luton Borough Council (n=1), Lateral Trust (n=1), Roma Trust (n=2), Link Community Centre (n=1), Luton and Dunstable Maternity Voices Partnership (n=1), Strategic Partnership in the East of England (n=1), and a healthcare professional with a Romanian background (n=1).

Professionals had been in their current employment between two months to two years, and described their roles as providing care or support for Roma people, some for all ages, some for young people and families only. The group typically described having worked hard to engage and build trust with the Luton Roma community, and this included those that were from a Roma background themselves.



## 4.0 THE FOCUS GROUPS: VIEWS OF THE ROMA COMMUNITY

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### KEY FINDINGS SUMMARY

- **The main health conditions causing concern for the Roma community**
  - Types of health conditions causing concern to Roma people
    - The majority of participants discussed how maternity and child healthcare, along with adult healthcare, were inadequate and how the Roma people were treated less favourably compared to other ethnic groups. This was a cause of concern.
  - Small numbers (two participants only) accessed preventative care for chronic conditions, and were satisfied with care.
    - Not many of the conditions listed in the focus group discussion guide, about chronic health conditions, such as diabetes, and obesity were discussed during the focus group discussions.
    - Overall there were not many expressions of satisfaction with healthcare services in Luton as the majority of focus group participants expressed dissatisfaction with services.
  - Emergency healthcare was much more frequently mentioned, and participants were generally dissatisfied by the quality of this care.
    - Participants' priorities were mother, baby and child health, and adult health. Overall there was poor satisfaction with care.
  - Unacceptable waiting for healthcare and inadequate quality of care.
    - Participants were not satisfied with healthcare provision, as they reported having to wait too long to be seen, quality of care was not good enough, language and communication problems, no access to a translator and less attention given to Roma people.
- **Barriers that prevent Roma people from accessing healthcare**
  - Knowledge of healthcare services.
    - The majority of participants did not know about the range of available healthcare services in Luton.
    - Participants often did not know how to refer to preventative healthcare, and they reported struggling to secure GP appointments.
  - Reasons for going 'back home' for healthcare.
    - Participants consistently reported a strong preference for travelling to Romania for healthcare. They explained this was because of long waiting times and the quality of care they receive in Luton.
  - Language and communication barriers.
    - The main barriers to accessing healthcare for Roma people interviewed stemmed from not speaking English, and not being able to access a healthcare professional or translator who could speak in Romanian. This resulted in difficulties and delays in setting up health appointments, delays in being seen, as well as difficulties in communication during appointments.
    - Participants told us that problems in accessing healthcare were exacerbated when staff gave them electronic devices to check into an appointment, make an appointment, or book a

translator, because they did not include a Romanian language option and therefore many reported not being able to use devices offered to accomplish these intended tasks.

- Perceived discrimination from service providers.
  - Almost all participants reported feeling they were treated differently and less favourably, on the grounds of being Roma.
  - Participants said they preferred to be called Roma, and not 'gypsy' or 'gipsy' which they consider insulting. They also disliked the term 'traveller'. Two participants commented that being Roma was equated to being called a 'gipsy' or 'gypsy' by people in Luton, when providing a detailed account about their perceptions of being treated differently and less favourably, due to being Roma.
  - Perceived discrimination was also linked to not being able to speak English. Participants discussed their experience of discrimination in relation to other ethno-national groups.
  - One participant explained she could not make an appointment due to being too young, and another participant felt she experienced double discrimination because she was Roma and disabled.
  - Participants did not express concern in relation to religious stigma or discrimination.
- **Suggestions for improving access to healthcare in Luton**
  - The need for more information on the range, referral routes to and location of healthcare services.
    - Participants discussed the need for information on the range, and location of healthcare services. Information should be provided in Romanian.
    - Suggestions for the best ways to provide this information included leaflets and flyers, videos, the internet, posters, GP, schools, discussion groups, information by telephone and post. Participants said all information should be provided in Romanian or other languages they understood.
  - Tackling issues of language and communication including the lack of availability of translators.
    - There was a consensus about the need for support tackling language and communication issues by providing translated information. Participants also emphasised the importance of having translators available to address the Romanian English language barrier.
  - Culturally competent and compassionate care from healthcare professionals.
    - Participants suggested that the term 'gipsy' should not be used on forms, and that healthcare professionals needed training to be more culturally competent and compassionate towards the Roma community in Luton.

## 4.1 The main health conditions causing concern for Roma community

Participants were asked whether they had any concern about specific chronic conditions, for example, high blood pressure, diabetes, overweight and obesity, managing long COVID symptoms and support to manage health. These conditions were not mentioned in the focus group discussions. Instead the majority of participants discussed maternity and child healthcare, and adult healthcare as inadequate and treated less favourably compared to other ethnic groups. This is discussed in more detail below:

### 4.1.1 Maternity and child healthcare

The majority of our participants were dissatisfied with maternity and child healthcare. For women aged 26-35, language difficulties and being unable to communicate effectively with healthcare professionals, came up as creating difficulty in the provision of adequate maternity and birthing care.

Amongst males aged 26-35 and 56+, and women aged 20-25 and 26-35, all gave examples of child or baby illness, with complaints about waiting hours, having to go to Romania to be helped, not being able to schedule an appointment by telephone, and having to take a sick child to the GP reception in order to be seen.

*“In the past I had a problem with my baby, the baby had a nosebleed and the emergency doctors made me wait for many hours and nobody helped me.” (Female, aged 26-35)*

*“My children, they had rashes, and I was told [it was] nothing, I just must wait for them to pass.” (Female, aged 26-35)*

*“They [Luton Doctors] don’t look after our children here the way doctors do in Romania. I had a case with one of my children and she was not looked after. All the doctors here did was look at the child for a bit and that was it, he [Doctor] sent us home saying there was nothing wrong...”. (Male, aged 45–55)*

*“I had to go to the GP reception with my sick child to show them how serious the situation was. I had an emergency, and no one paid any attention to me until I physically went to them without an appointment.” (Male, aged 56+)*

*“I’ve been to the hospital many times with my child, in the emergency room, and the people from the reception made me wait for hours...”*

*[You] are made to wait for hours, even if the children are vomiting, feverish, screaming, screaming in pain. The even bigger problem is when the receptionists [give] the excuse that there are not enough people to take care of the emergencies at that moment or that there are no doctors available. It doesn't seem normal to me.” (Female, aged 36-45)*

*“I did not have the benefit of an interpreter, my new-born baby was blue, vomiting and seemed limp, weak. I got very scared and started screaming for help, no one was touching my baby, no one explained to me what was going on, everyone just told me to stay calm that there was no problem with the baby. I asked for a translator, I asked to allow my husband to enter the room, because he speaks and understands English, but they refused, they just told me to wait for a translator to come and explain everything. I waited for hours and finally the baby was taken and put in an incubator, but the translator was still not given to me.” (Female, aged 36-45)*

#### 4.1.2 Adult healthcare

The majority of our participants felt that adult healthcare was inadequate. Women aged 20-25, 26-35, and 36-45, gave examples of adult health services not being ‘good enough’ in Luton.

Examples given of the types of health difficulties presented, include psoriasis which could not be resolved sufficiently in Luton, not being called back with results from a scan, and a mother-in-law whose bloods were not taken when they should have been, the latter linked to not having access to a translator:

*“I took my mother-in-law to the hospital, and they didn't even take her blood pressure... My mother-in-law said she felt her blood pressure was very high, she had health problems with her heart, and no one paid us any attention.” (Female, aged 36-45)*

*“I have 3 myocardial infarctions, I have 3 stems on my heart, and I am registered with the GP here in Luton... It would be a great help to me to have a translator at the GP, can you imagine how reassured I would be if there was someone who could understand me when I speak?” (Male, aged 65+)*

*“I sprained my hand and went to the hospital... at the time of the consultation I was not told anything concrete. After the consultation, they told me that everything was fine, that I could go home [even though] I was in a lot of pain.” (Male, aged 26-35)*

*“I had a bad ear infection and wanted to go to the GP. One Friday, I managed to get to the GP, but they didn't help me, they sent me home.” (Female, aged 36-45)*

*“They told me that after the back scan, I will get a call from the GP, and they will let me know the results. To this day I have not received an answer to my health problem.” (Female, aged 26-35)*

*“Many of the health service staff here in Luton, I have noticed, are incompetent.” (Male, aged 65+, with heart condition)*

#### **4.3 Barriers that prevent Roma people from accessing healthcare**

##### **4.3.1 Knowledge of healthcare services and referral routes**

Participants were asked about their awareness of the range of healthcare services available e.g. GPs, healthcare centres, contraception services, maternal health services, hospital A&E, hospital outpatient services and vaccination centres.

Participants in eight of the eleven focus groups stated they were aware of these services being available. Participants in the remaining three focus groups, did not have knowledge about healthcare services. Specifically, these were males aged 45-55, and women aged 36-45 and 56+. Those who knew about services gave information on how they knew about the available healthcare services:

*“From friends and those who have children I found out about the GP and the hospital and other centres in Luton.” (Male, aged 45-55)*

*“I personally found out from friends and some of the information through leaflets.” (Female, aged 26-35)*

In two of the focus groups, women aged 16-21 and 36-45, stated that they did not have any information available to them about services, and only one knew how to call emergency services, even when non-emergency care was needed. Additional comments from those stating they did not know about services included, ‘I don’t know who my GP is’, and ‘I don’t know how to hear about services’.

*“I personally have not heard about these services. I have not had anyone to teach me or give me information about them.” (Male, aged 20-25)*

*“There are no people to help inform people about health services in a way that we understand. I come here to a foreign country, I don't know the language and I don't know where to go, who to go to for more information about what I need.” (Male, aged 20-25)*

*“I don't know anything about these things.” (Female, aged 56+)*

*“No, because nobody told us, nobody explained these things to us.” (Female, aged 26-35)*

The focus group participants were asked about their knowledge of referral processes to healthcare services mentioned e.g. self-referral, making a GP appointment, GP referral to hospital, mental health services, where to go for information about these services e.g. GP, other health professionals, family/friends, children, media, internet, schools, community support groups (ask what groups i.e. Roma trust, informal WhatsApp groups).

Participants in six of the focus groups did not know how to be referred to services, including all of those same three focus groups who did not know about services existing. The additional three, who knew services existed but did not know how to be referred to them, consisted of women aged 16-21 and 26-35, and males aged 20-25. Those participants who did not know how to make referrals to services said that they contact emergency services because they do not know the referral process.

*“I call the emergency room and try to make an appointment [gynaecology]... I don't know where else to call.” (Female, aged 16-21)*

*“I don't know how to access [the services].” (Male, aged 20-25)*

*“We heard about these services, but we don't know how to access them.” (Males, aged 45-55)*

#### 4.3.2 Reasons for going ‘back home’ for healthcare

When participants compared healthcare services between Luton and Romania, there was a unanimous view that healthcare in Romania is better than in Luton. This view was based on long waiting times for appointments and a lack of attention and sensitivity from healthcare staff.

All of the participants reported it takes too long to set up an appointment, or it is not possible to make an appointment when needed. Focus group participants unanimously described waiting for an unacceptably long time to be seen:

*“You must wait a very long time and it doesn't seem normal to me, but otherwise I have a very good opinion about the health services here.”  
(Male, Aged 65+)*

*“When I want to make a GP appointment, I have to wait a very long time, I am handed from operator to operator, I am asked a lot of meaningless questions, and it doesn't help me at all.” (Female, aged 26-35)*

*“We wait for hours when it comes to any kind of medical service.”  
(Female, 20-25)*

*“There are quite a lot of problems within the health services in Luton... Appointments are quite hard to get, and you have to wait up to a few weeks to get an appointment.” (Male, aged 45–55)*

*“I was in a lot of pain and had to wait 3 days to be able to go to the GP.” (Female, aged 16-21)*

*“We are always delayed, and I don't know if this is because of our ethnicity or because we don't speak English well.” (Male, aged 45-55)*

*“[It] took two to three months to get an appointment. Things need to move faster, not wait months.” (Female, aged 65+)*

*“I waited for 3 hours for someone to answer the phone to get me an appointment at the GP. Finally, my [son] managed to get on the phone to get me an appointment after a few weeks. Another problem was when I was 4 minutes late for an appointment I had previously [made] with my GP, and the doctors there wouldn't see me because I was 4 minutes late. They told me I needed another appointment.” (Female, aged 65+)*

*“To get a simple GP appointment... the phone line is already busy and I'm automatically redirected to a hold situation, which usually lasts a few hours. It seems excessive to wait in line with the phone in my hand for 3 hours.” (Female, aged 36-45)*

Half of the focus group participants (mixed ages and genders), added that they were unable to manage to set up an appointment, when this was needed.



*“Sometimes I have even waited a few months to get a simple GP appointment (PEOPLE DIE AND DO NOT GET TO THE DOCTOR).” (Female, 26-35)*

The narrative extracts below demonstrate the strength of feeling among our focus group participants on the issue of quality of care from healthcare professionals.

*“Here we are not given the help we need; we are not given attention and everything moves very slowly... I always go home for this [medication].” (Male, aged 20-25)*

*“If a child has a serious health problem and I go with him to the hospital, to the emergency room, all the doctors will give him paracetamol.... I prefer to go home where the doctors are much more professional and much more attentive.” (Male, aged 26-35)*

*“Treatment here is not the same as treatment in Romania. I tried to take pills and the actual treatment here in Luton and it didn't do me any good, it doesn't compare to the one [services] in Romania.” (Male, aged 65+)*

*“I prefer to go home to Romania and treat both myself and my child if needed, rather than waste time at the GP here in Luton.” (Female, aged 26-35)*

*“Every time I asked for someone who could speak our language, I was told they didn't have the staff for that. I'm pregnant and I think I'm afraid to give birth in Luton because I don't get on with the doctors. At home I can have a quiet birth but here no one understands me, I would find it hard to give birth in Luton.” (Female, aged 26-35)*

*“I go home to get my health treatments, because here in Luton it takes too long to get an appointment with a doctor, for a medical service, or even to get treatment.” (Female, aged 16-21)*

Describing a situation in which the mother of a baby with a high temperature was told there was nothing to worry about in the UK:

*“In the U.K you can really die in days. [I] arrived in Romania to the doctor, when they saw the condition of the 8-month-old baby, they admitted her urgently.” (Female, aged 36-45)*

*“We don't know English and we are not given the attention we need to be able to carry out an investigation for our health.” (Female, aged 65+)*

*“I have been treated by the doctors here in Luton for a year, no improvement... I had to continue my investigations in Romania to make sure that my health would not worsen.” (Male, aged 65+)*

*"They don't know what treatment to give us and that's why I prefer to go home." (Female, aged 20-25)*

*"I prefer to go home for treatments." (Male, aged 45-55)*

*"By the time we were in Luton at the hospital, the child had a fever and large red spots... the doctor at the hospital did not prescribe any medication for the child, and sent us home.... The Romanian reacted immediately and took a stand towards the child's health condition." (Male, aged 45-55)*

*"The doctor who checked my child suggested that there was nothing wrong with the boy and that he was healthy. After we were sent home by the GP, my wife and I decided to go home to see what was wrong with our son. When we arrived in Romania at the doctor's, the hospital told us that the boy had an infection in his throat, that he had a cold and that some further investigations were done, and the child was diagnosed with a cold in his lungs." (Male, aged 45-55)*

*"I had psoriasis, and I was given many creams by the doctor here in Luton, but it still didn't go away... In Romania I had blood tests, was given another treatment and returned to Luton, and after some time my health improved." (Female, aged 20-25)*

Participants described their dissatisfaction with healthcare services in Luton:

*"I went to the hospital, had my hand x-rayed but to this day I still haven't got the result." (Female, aged 56+)*

*"I am not satisfied with the health services in Luton because most of the time these services are unprofessional. The quality of services is poor and from what I have observed, treating patients with superficiality and indifference is another big problem." (Male, aged 16-21)*

*"My water broke, I was ready to give birth at any moment and the doctors sent me home saying I wasn't ready yet, I had to come back the next day." (Female, aged 26-35)*

*"I have the impression that they do not put enough effort in helping those who need medical assistance." (Male, aged 16-21)*

*"After my parents were seen, the doctor there would send us home telling us that we have no serious problem, and we can go home because the problems will go away by themselves." (Male, aged 16-21)*

*"They don't have the patience to help you 100%. They treat you superficially and sometimes with indifference, especially if you don't know English." (Male, aged 20-25)*

*"They don't take an interest and they treat you like a nobody."  
(Female, aged 36-45)*

*"There is a very big lack of communication between the people in charge of health services here, and we must suffer enormously because of this." (Male, aged 56+)*

*"The system in Luton health services is deplorable. I have never had my problems solved." (Female, aged 20-25)*

*"The medical system is rubbish." (Male, aged 45-55)*

*"The staff leave a lot to be desired." (Female, aged 20-25)*

*"They don't care, I have always been treated with indifference and not because of my ethnicity or English language, but simply because the doctors [are] slow and indifferent." (Female, aged 20-25)*

*"I told them I had pain in my abdomen, my navel, and the doctors there recommended paracetamol...I tried to solve my problem here and I noticed that I couldn't, I went to Romania to solve the health problem I had." (Male, aged 20-25)*

*"If I go sick with hepatitis, I am prescribed paracetamol." (Male, aged 16-21)*

*"If you have heart problems or any other health problem, you will be prescribed paracetamol." (Female, aged 36-45)*

A small number of participants mentioned they trust Luton doctors less than those in Romania:

*"Yes, I felt safe at home, and I trusted the doctors there more."  
(Female, aged 20-25)*

The majority of participants also reported language barriers as a reason for returning 'back home' to Romania or elsewhere for healthcare. This is discussed in more detail in the next section.

#### 4.2.3 Language and communication barriers

The main barriers to accessing healthcare for Roma people interviewed stemmed from language and communication problems. All participants unanimously felt that they had difficulty communicating because they did not speak English and healthcare professionals did not speak Romanian. Difficulty in communication led to delays in

help-seeking i.e. making appointments and understanding each other during consultations.

*“It was quite difficult for us because we can’t communicate at a better level in English.” (Male, aged 45-55)*

*“We don’t know English and can’t speak it at a level where we can have decent communication with the health services in Luton, and they don’t provide us with an interpreter to help us with our situation.” (Male, aged 45-55)*

*“I didn’t understand much of what they told me there.” (Male, 20-25)*

*“Yes, definitely, English is a problem.” (Male, aged 45–55)*

*“If communication was better between me and the doctors here, 99% of my problems [would be] solved.” (Male, aged 20-25)*

A common remark made by women aged 46-55, was that ‘nothing else would help, just a translator’, and similarly, from the focus group of women aged 16-21, a translator was said to be a solution that would ‘definitely solve all of my problems’. Amongst women aged 26-35, one commented that having a translator available ‘would change everything’. Expressions of confidence in improvement if translators were available is further presented in the quotes below:

*“When you call the GP to make an appointment and you try to explain the problem you have, and you don’t know how to express yourself properly, they make you wait for hours for an operator to pick you up.” (Male, aged 20-25)*

*“If there was a phone number where our parents could call whenever they need a translator, many problems would disappear.” (Male, aged 16-21)*

*“It [translator access] would solve all the problems.” (Female, aged 16-21)*

*“Sometimes when we don’t know how to express ourselves properly in English, the health service people in Luton take advantage of this and that’s why we must wait so long for an appointment.” (Male, aged 56+)*

*“There should be a help centre in Luton health centres, where we can find a translator who can help us.” (Male aged 45-55)*

*"I have a problem with getting GP appointments. We Roma people don't speak or read English. We are not given a translator to be able to communicate better with people in the health services in Luton and when I try to call to get an appointment at the GP, they redirect me to their webpage to make the appointment online. I don't know how to navigate the internet, I can't manage on my own to get an appointment at the GP." (Female, aged 36-45)*

The majority of focus group participants explained that they relied on family and friends to translate written materials and during consultations. Some males aged 16-21 stated they were expected to support their family with translation, especially their parents. Some challenges related to this were having poor English themselves, therefore struggling to understand communication and translate effectively, and struggling to fit this task around working or study schedules.

Three of the groups, all males, aged 16-21, 26-35, and 65+, stated they had no-one to help them, and therefore they needed to manage alone.

*"I don't get any help from anyone, I don't know anyone who can help me with English." (Male, aged 65+)*

*"I always must call a friend who knows English to help me get appointments and accompany me to the GP or hospital." (Male, 20-25)*

*"If I can't manage English, I take someone with me who speaks fluent English." (Male, aged 65+)*

*"She [my daughter] helps me whenever I need it, within her available time because she works a lot... she always accompanies me and helps me with English translation." (Male, aged 65+)*

There were some limitations to having friends and family translate, even when they were available to do so. For example, a participant from one focus group, a women aged 46-55, stated that her children struggled to speak good English, which meant that having them translate was not adequate, whether in person, or when expected to use electronic devices. Another participant from this same focus group offered the view that 'nothing else would help, just a translator'. A female participant aged 16-21, gave an example that relying on a friend to set up an appointment on her behalf meant a delay of four days in accessing services.

*“The children help us; they speak a little English”. (Female, aged 56+)*

*“I take my children every time with me, they can speak a little English. They do better than I do.” (Female, aged 46-55)*

*“It is harder to translate to our parents and problems often arise because we understand what the doctor wants to say, but sometimes our parents don't understand us when we want to translate certain phrases from English into Romanian.” (Male, aged 16-21)*

*“It's not easy at all. I have school, I have a busy schedule, it's not easy for me to go whenever they need help translating because my parents don't understand when I'm trying to explain to them what the people in the health services here are saying.” (Male, aged 16-21)*

*“It's hard for me, if my child is not available to me then I can't go to the doctor either. I depend on her and her schedule.” (Male, aged 65+)*

*“We filled in the form together to get a translator and I was subsequently granted the translator, but I lost 4 days when I needed the GP appointment because I had to wait for my friend to help me because he didn't have time.” (Female, aged 16-21)*

In four of the focus group discussions participants (women aged 16-21, 26-35, 36-46, and 46-55) reported that the language problems were exacerbated when they were given an electronic device, to check in for an appointment, to book an appointment or a translator because the electronic devices did not have a Romanian language option and therefore many reported not being able to use devices offered to accomplish these intended tasks.

*“I was not provided with a translator. I was told to go online to get an appointment. I was also told to fill out a form to get a translator so that I would later be listed in their database with this little help. The form must be completed in English and on the online platform. I can't manage to do these things myself. I don't know how to navigate online and I don't know English either.” (Female, aged 16-21)*

*“Even on those devices where you make an appointment or must enter your data at the hospital when they ask you there, it says in [includes] all possible languages but not in Romanian. It was really annoying when I noticed that you could change the language you wanted the tablet to be in but there was no Romanian.” (Female, aged 26-35)*

#### 4.2.4 Perceived discrimination from service providers

Almost all participants reported feeling they were treated differently, and less favourably, on the grounds of being Roma. Participants said that they preferred

to be called Roma, and not 'gypsy' or 'gipsy', or 'traveller'. Two participants commented that being Roma was equated to being called a 'gipsy' or 'gypsy' by people in Luton, when providing a detailed account about their perceptions of being treated differently and less favourably, due to being Roma.

*"The problem is that we Roma are called Romanian Gipsy here in Luton." (Male, aged 56+)*

*"...because they call us gypsies." (Female, aged 36-45)*

One focus group participant explained that she was not called for a follow-up appointment because:

*"...I am a gypsy and I don't speak English." (Female, aged 36-45)*

The perception of Roma people being treated less well seemed to be linked to differences in the provision of translation services and acknowledgement of the language on electronic devices when compared to other ethno-national groups.

Women aged 26-35 also talked about feeling 'rushed' and 'pushed away' by doctors. Women aged 20-25 expressed this as feeling 'scolded' and 'sent away'. Two groups (women aged 16-21, and men aged 20-25) reported feeling either 'disliked', or that doctors were less 'patient' with them, for reasons of both being Roma in addition to the language barriers. Males aged 56+ added that being Roma has meant a longer wait for health appointments, compared to other ethno-national groups. Women aged 36-45 expressed they felt 'understood' in Romania, but not here.

*"I told the lady there that I didn't know how to communicate in English and that I would like an interpreter. She told me that she could not provide translators and to come back the next day. At that moment I felt discriminated against." (Female, aged 16-21)*

*"There are differences between our ethnicity and other types of ethnicities. Always when we go to the GP, we wait for hours to be picked up, the same when we try to make GP appointments." (Male, aged 20-25)*

*"I have noticed that there is a discrimination between us Roma and others who have other ethnicities." (Female, aged 26-35)*

*"I have seen that differences are made between us and those of other nationalities, ethnicities." (Male, aged 26-35)*

*"I would [have] definitely be [been] discriminated against because I don't know how to explain those [my] symptoms in English and I can't*



*find a person there who can understand me or help me in that case.”*  
(Male, aged 26-35)

*“When I try to explain my problem, I don't know how to speak English very well, I need time to explain, the doctors or the people I talk to on the phone about my health problem don't let me finish what I am trying to explain, and they try to rush me somehow. I feel marginalized and pushed away.”* (Female, aged 26-35)

*“The lady at the reception noticed that I was Roma person and I noticed that she immediately changed her look.”* (Female, aged 56+)

*“I would like us all to be treated equally, regardless of our nationality.”*  
(Female, aged 36-45)

*“I asked for information about the child's health, and she kept telling me in English to wait. Every time I asked her a question, she always replied that I had to wait. They would just tell me to wait and spoke amongst themselves in their native language, not English. It didn't seem right; I had the impression that they were talking about me because their eyes were always directed towards me when they were talking to each other... I expected them to help me with a translator, not to have to wait an hour and a half for nothing. Why didn't they take the necessary attitude to do their best to understand what I want[ed] to say and what my problems are [were]? It didn't seem fair at all.”*  
(Male, aged 20-25)

*“I think there is discrimination in this respect. For example, I tried to get a GP appointment and got it after 3 months, and [whereas] a Muslim gets it after a few days. (Male, aged 56+)*

*“I have noticed that they prefer to treat those who have the same ethnicity as theirs first and then treat the rest of us Roma.”* (Male, aged 56+)

*“I think we are discriminated against because of our Roma ethnicity and the fact that we are not integrated into society like everyone else here, they still look at us with different eyes when they see us and find out that we are Roma... Society has always marginalised us and has never given us a chance.”* (Male, aged 56+)

*“There are very big differences between us Roma and those of other ethnicities. There are many problems of many kinds when people find out or notice that our ethnicity is Roma. Many abusive things have happened because of this, and we are not welcomed as we should be everywhere.”* (Male, aged 45-55)

*“I wanted to go and get a job, find a job... We were interviewed, but I think because of our ethnicity, we were not selected for the job. We were fit for work and wanted to work, it was physical work, but we were passed over. The same thing happened to us when we went to the hospital. The people at the hospital noticed that we were Roma people, and we were not given the necessary attention there either.*

*Wherever we try to go to integrate into this society, we are often rejected.” (Male, aged 45-55)*

*“We are Roma and wherever we go and [when we] want to access certain services in the UK, I have always been turned away. It seems to me that everyone in the system here in Luton has something against the Roma.” (Male aged 45-55)*

*“There is discrimination between our ethnicity, Roma, and other people of different ethnicities.” (Male, aged 45-55)*

*“I also feel that small differences are made between Roma people and those of different ethnicities.” (Female, aged 20-25)*

*“I have a heart condition. I went there [to the GP] with a heart attack and my brother helped me to get to the GP. I had high blood pressure, fainted in the house and my brother found me lying on the floor. If I didn't go to the doctor in Romania to change my treatment and have other medical investigations, there is the possibility that I would [have] died at home. Why don't they [GPs] take care of people as they should regardless of the nationality of the person?” (Female, aged 36-45)*

In two focus groups (males aged 16-21 and women aged 46-55) there were mixed views about discrimination, where some participants felt that they did not know if their experiences amounted to discrimination.

*“I don't know whether or not discrimination is made.” (Male, aged 16-21)*

Among males aged 45-55, one reported feeling treated less favourably compared to other ethnic groups:

*“We are always delayed, and I don't know if this is because of our ethnicity or because we don't speak English well.” (Male, aged 45-55)*

One participant explained she could not make an appointment due to being too young and another participant felt she experienced double discrimination because she was Roma and disabled.

*“Not being of age, [means] I can't access the online platform.” (Female, aged 16-21)*

*"I am a person declared disabled, and I feel discriminated". (Female, aged 36-45)*

Participants did not express concern in relation to religious stigma or discrimination.

#### **4.4 Suggestions for improving access to healthcare in Luton**

The main themes emerging for suggestions for improving access to healthcare in Luton were: the need for more information on the range and location of healthcare services, tackling issues of language and communication including the lack of availability of translators and improved advice, more culturally competent and compassionate care from healthcare professionals.

##### **4.4.1 The need for more information on the range, referral routes to and location of healthcare services**

Participants suggested that the information requested was about the range, referral routes and location of healthcare services available. Overall there was no discussion of prevention services, rehabilitation services and mental health services and the focus of discussion was GP or emergency services. Participants explained that not everyone from the Roma community is registered with a GP, so providing public information about how to access a GP, and the additional range and referral to healthcare services is needed.

*"I personally have not heard about these services. I have not had anyone to teach me or give me information about them." (Male, aged 20-25)*

*"There are no people to help inform people about health services in a way that we understand. I come here to a foreign country, I don't know the language and I don't know where to go, who to go to for more information about what I need." (Male, aged 20-25)*

*"I don't know anything about these things." (Female, aged 56+)*

*"No, because nobody told us, nobody explained these things to us." (Female, aged 26-35)*

#### **Suggestions for the best ways to provide this information**

Participants gave suggestions for the best ways to provide this information. These included leaflets, videos, the internet, other ways such as in schools, and information

by telephone. They made explicit that this information should be in Romanian or a language that could be understood. These are discussed in more detail below.

### *Leaflets and flyers*

Participants in eight of the eleven focus groups provided an opinion about leaflets or flyers as a means to providing healthcare information to Roma people. Women aged 46-55 remarked that leaflets written in English only, are not useful. Males aged 16-21 stated that having both English and Romanian (or another language that can be understood) versions of these would be most beneficial. All others who contributed with information about leaflets or flyers (women aged 16-21, 20-25, 26-35, 56+ and males aged 20-25, 45-55, and 56+) felt that these should be written in Romanian (or other languages that can be understood) in order to be most useful to Roma people.

*“It would help me if there was information available in Romani and not just in English.” (Male, aged 20-25)*

*“I still get leaflets from there [GP] which my friends translate for me.” (Male, aged 65+)*

*“It would be helpful if we could get information about health services in Luton through leaflets, but in Romanian.” (Female, aged 20-25)*

### *Videos*

In focus group 10, males aged 20-25 suggested that videos would be helpful, if these could provide information in Romanian (or other languages that can be understood).

*“I think that information about health services in Luton should be provided through videos and leaflets in Romanian.” (Male, aged 20-25)*

### *The internet*

Overall participants in six of the eleven focus groups (women aged 16-21 and 20-25, and males aged 16-21, 20-25, 26-35, and 56+), said that they accessed information about health symptoms and healthcare services on the internet.

Males aged 16-21 and 26-35, and women aged 20-25, stated that the internet, in English, had been informative to them because they had some understanding of

English. They said that providing information on the internet in Romanian would be beneficial to them and other members of the Roma community with limited English language fluency.

*“The internet helps us, a lot.” (Female, aged 20-25)*

Males aged 16-21 felt the internet would not help their parents to better understand healthcare systems in Luton.

*Other ways of providing information:*

- *‘Posters would be helpful if in Romanian (or other languages that can be understood)’.* Women aged 26-35 suggested that having posters written in Romanian could be a useful way to present information in the future.
- *‘[The] GP already helps me to access services’.* Another comment came from one participant in a focus group for women aged 46-55, stating that her GP had helped her with making a referral to other services.
- *‘Schools would be helpful, if they gave information’.* One focus group (women aged 20-25) suggested that accessing information on healthcare via schools could be useful.
- *‘More Roma discussion groups would be helpful’.* Seven of the 11 focus groups agreed that being given an opportunity to learn information in a discussion group setting, similar to the focus group itself, using Romanian language, or other languages that can be understood, would be useful to them.
- *‘Information by telephone and post’.* Women aged 65+ felt that it may be helpful to receive information about health services by telephone and by post. Women aged 46-55 also expressed a preference for information by post rather than the internet.

*“To provide a translator, or access to a telephone translator, or to provide information through the Roma communication centres or videos in Romanian, it would be very helpful to us.” (Males, aged 20-25)*

#### 4.4.2 Tackling issues of language and communication

As discussed above, there was unanimous support for tackling language and communication issues by providing translated information. Participants also emphasised the importance of having translators available to address the Romanian-English language barrier.

*“[An interpreter available at Luton health centres] would take away most of the problems and challenges we face every time we want to access these services.” (Males, aged 20-25)*

*“I believe that every person in the Luton Roma community needs the support [from a translator] to access health services to their full potential and feel safe. To be confident that if they go to the doctor, or hospital, there will be someone who understands them and with whom they can communicate.” (Male, aged 56+)*

*“A translator would be helpful to be able to talk properly with the health services.” (Female, aged 20-25)*

*“We don't understand each other, the doctor doesn't know what hurts me, I don't know how to explain.” (Female, aged 56+)*

Males aged 16-21 suggested that translators should be available at health centres during home visits, and telephone services should be available in Romanian so telephone appointments could be booked more easily. Women aged 16-21, and males aged 20-25, both added that their preference would be to have face-to-face translators, or translators on hand via telephone if this was not possible.

*“It [a translator] would put an end to all the problems we have in the health services in Luton.” (Male aged 45-55)*

*“A translator would give us the attention we need.” (Female, aged 36-45)*

*“We don't know how to express ourselves as we should in English and maybe this also prevents us from having good*

*communication with the health services, but we are not provided with a translator either.” (Male, aged 45-55)*

*“I would just like them to supplement all the health service institutions in Luton with translators. That way we can communicate much better with the people there and I think that way we will not be discriminated against.” (Female, aged 36-45)*

#### 4.4.3 Cultural competence and compassionate care from healthcare professionals

The sections above have highlighted that participants said they were stigmatised for being Roma and disliked being called ‘gipsy’, and consequently felt discriminated and treated poorly by healthcare professionals when compared to other ethno-national groups. This was exacerbated by language barriers. They suggested that the term ‘gipsy’ should not be used on forms, and that healthcare professionals needed training to be more culturally competent and compassionate towards the Roma community in Luton.



## 5.0 THE INTERVIEWS: VIEWS OF PROFESSIONALS WHO WORK WITH THE ROMA COMMUNITY

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### KEY FINDINGS SUMMARY

- **Views of professionals on barriers to healthcare for the Roma community**
  - Knowledge about available services.
    - There was a unanimous view that Roma people do not have a basic awareness of types of healthcare services, or how to go about being referred to healthcare services in Luton.
  - Difficulties accessing GP and other health appointments.
    - Professionals expressed concern that the Roma community do not know how to set up and attend healthcare appointments. They linked this to the challenges the Roma community experienced with poor English fluency, low levels of education, poor digital literacy and a limited understanding of how the healthcare system in the UK works.
  - Language and communication problems.
    - Professionals working with the Roma community acknowledged language and communication as being a significant barrier for the Roma community/people accessing healthcare in Luton.
    - Professionals said that there was a lack of translators available to support the Roma community in Luton.
    - Digital barriers were discussed in addition to language barriers.
  - Inadequate care and discrimination from healthcare professionals.
    - Professionals explained that inadequate care and discrimination experienced by the Roma community resulted in many going 'home' for healthcare.
  - Concerns and additional vulnerability of the Roma community.
    - Some professionals expressed concern that Roma people may be prone to additional vulnerabilities such as exploitation including sexual exploitation, contraception and contraceptive services, vaccinations and chronic conditions.
    - Some professionals provided views about specific chronic conditions among Roma people, e.g. high blood pressure, diabetes, overweight and obesity managing long COVID symptoms, and support to manage health.
    - Professionals explained that religion may underpin some of the healthcare issues around not wanting to be vaccinated, or to engage in preventative healthcare.
- **Suggestions for improving access to healthcare in Luton**
  - Improve literacy on preventative healthcare.
    - Professionals argued that engaging the Roma people to improve health literacy on prevention was imperative. They also argued it was the responsibility of healthcare professionals to ensure early intervention to avoid the need for emergency care.
    - Professionals felt that Roma people cannot manage to access to healthcare independently, for reasons of language fluency, poor

digital skills level, and a lack of experience about how healthcare systems work in the UK.

- Professionals unanimously discussed the need for cultural competency training for professionals and providers, in order to manage the perceived discrimination experienced by the Roma community when accessing healthcare in Luton.
- Professionals gave suggestions for the best way to provide cultural competency training for healthcare professionals and providers. These suggestions included training for professionals to understand that UK services don't make sense to Roma people, training for professionals and others to coach Roma people on how to ask for what is needed in English during a health appointment, and community conversation to build trust with the Roma community.

## **5.1 Views of professionals on barriers to accessing healthcare for the Roma community**

The main themes for professionals who work with the Roma community were knowledge about available services, difficulties accessing GP and other appointments, language and communication problems, inadequate care and discrimination from healthcare professionals, and concerns about additional vulnerability of the Roma community.

### **5.1.1 Knowledge about available services**

Professionals held a unanimous view that Roma people do not have a basic awareness of types of healthcare services or how to go about being referred.

One professional added this may be because they don't personally know any health professionals. Another suggested they wouldn't manage the task of referring unless helped to do so:

*"I don't think so, because I think the first thing is lack of professional[ism] within their community. [That] is where the barriers are, isn't it? So that, you know, they don't have a professional network." (P1)*

*"No, I don't think they do." (P1)*

*"I very much doubt it. I don't know many people that really understand that." [referrals to services] (P9)*

*"Without us, they're completely unable to access the system. We are going with them in person. At the GP practices, we are making their medical appointments, we are requesting medical prescriptions for them. We are sometimes going to the Luton and Dunstable Hospital to the emergency room with them to make sure they will be fine." (P3)*

*"I would say the Roma have no knowledge of the services, almost no knowledge." (P3)*

*"Unless someone would take them through the referral process and we sit next to them and help them fill it in, but they wouldn't manage on their own. The only person that could actually help them or could do a referral is their GP. But the GP would have to get in touch with them. And you know, it's a language problem, it's an access problem." (P3)*

*"The problem with the Roma community is because [that] they don't know there are other services. They don't know how they can ask for other investigations." (P4)*

*"I don't get the impression there is loads of real knowledge about services." (P9)*

*"I don't generally see Roma women accessing like antenatal classes." (P7)*

*"I think a lot of them weren't [aren't] aware of what was available." (P7)*

*"...definitely [the] Roma Community is not aware about the available healthcare services in Luton." (P2)*

*"The GPs are completely unacceptable. So, they don't get information about these services and even if they manage to access these services, they wouldn't be able to get in touch with anyone." (P3)*

*"...they also don't know about the services." (P4)*

*"Maternity services. They're aware about maternity services because there is no other choice but for contraception... for some mental health services... they don't know... Absolutely not. They are not aware." (P2)*

*"They would not know where to go for the appointments." (P4)*

*"She didn't know what the difference was being a social worker, a midwife, a health visitor, and she didn't know what all the different roles were. And I think that's because people don't explain all [what] their roles are. When you come from a different country where, you know, your access to medical care is quite limited. Um, you know,*

*coming here... I think ultimately there's just real confusion about what access there is to care and what's available, what's free." (P9)*

Referring to registering a pregnancy P4 explained that Roma women register very late;

*"In the Roma community the pregnant women they are late. Registered. Very late." (P4)*

*They have expectations [about how] they want the GP to solve their problems [so] it's about making them aware [of] other services because once they know about other services, for example, the eye clinic, they don't want their GP again...it's about making them aware...*

*"They don't trust that we provide information that's accessible to them in a language that they understand, in a format that they understand, in the content that they understand."(P6)*

#### 5.1.2 Difficulties accessing GP and other appointments

Professionals expressed concern that the Roma community do not know how to set up and attend healthcare appointments. They linked this to the challenges the Roma community experienced with poor English fluency (discussed in section 5.1.3), low levels of education and digital skills, and knowledge of the healthcare system in the UK, including cost of services.

##### *Low levels of education and digital skills*

*"GP's have not always got the capacity or the understanding [or] the tolerance to support those women [in] an appropriate way. If they can't read, haven't got a smart phone, can't scan a QR code, [then] there's a lot of barriers in that on their own. [The environment is] isolating, not supportive, not trusting. So, [I] won't go again because of that experience." (P7)*

*"But they are often an excluded community on account of some lack of digital skills." (P8)*

*"So, and again, the same when we were talking about the perinatal mental health referral, that's a self-referral system as well. And again, you can do that online and you can change that to Romanian actually, but then you still need to have access to a laptop, you still need to be able to use a computer, you need to understand what it's asking you to do and digital exclusion is such a big thing. I think we shouldn't have [the] presumption that people have got access to that site."(P9)*

## Knowledge and cost of services

*"I think generally going to the GP can be quite challenging. Definitely there's real confusion about what different practitioners do and this came up in one of the sessions that we ran." (P9)*

*"And I think the response of what we've always had is that there is confusion about accessing services. There's definitely confusion with payment now so, for example, I was asked what's the cheapest way to give birth? Because people are concerned about charging [understanding the difference between NHS and private healthcare]." (P9)*

*"Sometimes they find it [as] difficult as booking GP appointments or speaking with those services, but I think they are starting to know more about them [contraception clinics]." (P5)*

*"Another big barrier was accessing the GP, getting appointments and being able to get into the GP surgery..." (P6)*

*"[Understanding] of different health professionals and because there's barriers with getting access to GP surgeries to have it goes onto the services and I'm not sure there's a huge amount of awareness that's the ones that are more educated, more literate. [Lack of awareness, even among those more educated]." (P7)*

*"[They return] back to their countries to get prescriptions because they trust that [what they are given], because they weren't aware of or didn't have access to what was available here so a big barrier is understanding our NHS system and how it can work for them." (P6)*

Professionals also said that short GP appointments did not enable effective communication:

*"The limited time of 10 minutes per appointment is not enough." (P4)*

### 5.1.3 Language and communication problems

Like the focus group participants, the professionals working with them acknowledged language and communication as being a significant barrier for the Roma community/people accessing healthcare in Luton.

*"The language barrier. Because they cannot express themselves, they even don't know what is in the hospital." (P4)*

*"The main problem they face is communication. If they haven't been able to speak good English and haven't been able to learn to read English." (P8)*

*"... a lot of the community can't read their own language. So that creates massive barriers." (P7)*

*"Language is always the problem." (P3)*

*"Sometimes things get lost in translation." (P5)*

*"So even from the first moment they try to enter the GP surgery they turn back because nobody speaks their language." (P3)*

*"Having someone there who speaks the language." (P3)*

*"Well, a lot of the women that we met [meet] with are illiterate so even if you translate things, they can't read what's been translated." (P6)*

*"I think back home to address and because of their language and comfort, you know, they feel they're able to, you know, communicate openly, and explain their illness and their private issues confidently and openly with them." (P1)*

*"I think the first [challenge] is the language. Language is the first barrier. Culture, you know, is a big barrier for them and also lack of communication. So, whatever health-related information's out there [it] is still being produced in a traditional manner and thinking Roma is just another... You must look at your customer." (P1)*

*"Also, if you go, you know, then things are in the right languages is a system that [they're] used to using. [The advantages of going home for healthcare services]." (P9)*

*"They're going back to their country because they can explain themselves in their own language. And it's easy to find a doctor to tell what you feel and how you feel in your own language." (P4)*

*"It is very hard to pass the reception at the GP surgery and it is very hard to communicate with them in any way. So, they are completely limited from a language point of view. So, they have no access in a way they could claim. The Roma that come to Luton, have no real access to the GP surgeries." (P3)*

*"Well, I think the difficulties that they encountered was a lack of English language, lack of awareness of how to access health authorities, doctors and hospitals. So that would be the first thing t[to sort out], a general unawareness, how you go about getting medical help." (P8)*

*“And difficult to get into a GP service, particularly to make appointments if English is not your first language.” (P9)*

Professionals said that there was a lack of translators available to support the Luton Roma community and that improved training for translators, including Roma people as service providers, could help:

*“I don't know how they recruited translators, but probably it should be someone with training in that particular field, not someone who simply speaks the language.” (P3)*

*“Nowhere does it say you can ask for an interpreter. It's a free service, so people might not know that [it's] a free service.” (P9)*

*“Second of all, it would be really important to have a Roma person inside who understands the culture, right, of the Roma.” (P3)*

P7 explained that the Roma community speak many languages, depending on their country of origin which complicates translation. In addition many of the Roma community cannot read their vernacular;

*“And it's a mistranslation, which is such a barrier because there are so many communities in Luton, and so it's an incredibly hard thing to do. And once you've translated something they can't read, it needs to be audio visual...I know on the website there's a tool that can then translate [it] back again. So that's a big barrier the translation.” (P7)*

*“So probably it should be in their language to understand the pathways to go there, they might not read because some of the Roma community, they are not educated.” (P4)*

*“[They should be] able to access translators when they come in at any point of time and during their care.” (P6)*

*“Having translations that work. The translation service often doesn't turn up or they don't translate appropriately into the translation based on the translated speech rather than their advice from what they're being offered. It's not a fit-for-purpose service.” (P7)*

Two participants discussed digital barriers in addition to language barriers.

*“Yeah, when it comes to making an appointment, most of the GP surgeries here in Luton have an online appointment system... almost all the Roma [people] have no digital skills.” (P3)*

*“They are not doing the repeat prescription.” (P4)*

#### 5.1.4 Inadequate care and discrimination from healthcare professionals

Professionals explained that inadequate care and discrimination experienced by the Roma community resulted in many going 'home' for healthcare.

*"So that's why many Roma people decide to go to Romania to seek treatment rather than staying here, because they know in [the] UK, [and] in Luton especially, it's almost impossible to get treatment when you need it." (P3)*

*"I have three more women who were pregnant, decided to go to Romania and give birth, and they'll come back after they give birth because here, [where] they don't speak English, [they cannot access the care they need]. [It] is completely unacceptable, the system as it is right now. It is completely unacceptable, especially for the Roma." (P3)*

*"People consider that they are not treated equally." (P4)*

One professional described a case in which a young child died, despite the family attempting to seek healthcare. This example seemed to illustrate the seriousness of the impact of difficulties for this group in accessing adequate care, not only due to their lost child, but the family were then accused of wrongdoing, and as a result the police were involved, after their child had died. Another example shared was about a woman in labour, who was not allowed a family member to join her for the birth, when they could have helped to translate for her.

Finally, although health services are free in the UK, and require being paid for 'back home', professionals felt that inadequate care and perceptions of stigma from healthcare staff meant that the Roma community/people preferred going back home for healthcare.

*"You might choose to go back ...[to] your country to pay for the service, for the health service, because you can explain and pursue the doctor to give you an outcome straight away because you pay for the service." (P4)*

*"So, the first reason is that they can speak to a doctor in the national language... But also, they [have] a higher [level of] trust in their actual doctors." (P8)*



*"I think it's just that it's easier and it's a service that [they] say they can pay for that service and be seen the same day. Whereas here it's quite a complex system, isn't it? So, for example, if you have an appointment and you need to see a consultant, you then have to be referred to the hospital, then that could take quite a few weeks and then you have that appointment and there'll be follow-up things. So, you can be talking for several months before getting a diagnosis. Whereas if you go back and I know colleagues that do this when they get paid and if you go back, you can be seen the same day by the consultant and have an answer that day. So yeah, it's a quicker system." (P9)*

*"Things are quite expensive here. So, if it is not provided for free, then definitely it is a major issue." (P1)*

*"Usually eastern European patients, especially, if they try, for example, to follow up or book an appointment with us and they don't manage, I have seen cases like that where people instead chose to fly out to their countries. One of the reasons might be that it is accessible. Because it is a short distance flight which is quite cheap so they can actually, and those services don't cost as much as they do here so when it's something that can be done with a consultant people will come back and get it done from here but it's different because sometimes it's quicker to see a consultant in their country. Then it's another problem about explaining, we can just see a specialist here, those are the waiting times, some are happy with that, and some don't want to wait that much." (P5)*

#### 5.1.5 Concerns and additional vulnerability and illnesses

Some professionals expressed concern that Roma people may be prone to additional vulnerabilities and illnesses, such as sexual exploitation, contraception services, contraception use, vaccinations and chronic conditions. These are discussed in more detail in the sections below.

##### *Concerns about exploitation including sexual exploitation and begging*

Some professionals discussed concerns that Roma women may be more vulnerable and prone to exploitation, as trafficked sex workers have been seen begging on the streets of Luton.

*"Give you an example that women, if you just go outside here now, they're begging literally they're on the street now. Right. So, the enforcement team I work with in the council obviously gets tired of that. How much they can do. The Roma Trust will not be able to cope with them..." (P1)*

P8 explained that women who get pregnant outside of marriage have the potential to be ostracised, which is another source of vulnerability:

*“Some people become suddenly very isolated from...[their communities], from their own families,, for example, some Roma women, if they got pregnant, [and] they shouldn't have got pregnant, they can suddenly be ostracized by their own people, become extremely, extremely vulnerable. So, we have to see, but we have to see their health in the context of the whole circumstances of their lives.” (P8)*

*“But also there's fear there..., when you know the things that they have to go through like forced sterilization, all the information, all the things that were in the media about, you know, Roma, ‘gypsy’ or ‘traveller’ communities, negativism, there's a lot of negativity.” (P9)*

One professional explained that begging was the norm among Roman women and that there was limited incentive to change this behaviour:

*“So, it's quite tough, especially for the women has [who have] been trapped in [the] sex trade, trapped in begging because I did some work with addressing the begging issue, .... They think that's what you do to survive in this world. You beg! They don't have any dignity or shame [as] in other communities who find that very shameful. To them, coming home from begging for the money is like coming home from doing a day's job. Right. So that's the challenge for them.” (P1)*

#### *Contraception, contraception services and vaccinations*

Professionals explained contraception and contraception services were not talked about, nor felt to be necessary among Roma people themselves.

*“Talking about contraceptives is taboo.” (P3)*

*“Even for the prevention of the pregnancy they take, I haven't heard one person saying I want to try to prevent the pregnancy.” (P4)*

*“There is high resistance for the vaccinations.” (P5)*

*“They believed that the vaccine was a government plot to kill them.” (P8)*

Many professionals expressed concern that the Roma community are not typically taking vaccines across a range of conditions, from COVID-19 to child health. Some professionals tried to make sense of why this is:

*"Historically... The Roma [community] has been the victim of some terrible, terrible misuse in media, in medical experiments in the past, which scarred them." (P1)*

*"Even those who are going to the level of attending school, they are not registering children at school, so they don't get the pre-school booster or vaccination. So [there] are all these issues with not knowing the legislation, not knowing the process, and not knowing the system, because they used to live freely in every country they travelled." (P4)*

*"Most of the parents do not want to vaccinate their children, and this is a real problem within the community... they're very reticent to get vaccinated. So, they would never get vaccinated because they don't understand the real benefits. And that's something that we really need to tackle." (P3)*

*"Vaccinations are major hesitancy. They think they don't need it and it can be very harmful. I'm not saying for all of them but compared to the general population." (P5)*

*"They were scared about vaccine[s] because of information that had [has] been shared from Romania. And it was often experts, experts coming in, talking and telling them they had to have this, it wasn't a trust building exercise. It wasn't okay." (P9)*

*"In the country of origin, things like vaccines aren't actively promoted.... But talking about the reasons why, you know, vaccines are really important [is essential]." (P6)*

*"Because in their country of origin they don't access those things... There's this view that you could harm your baby. So, there's that. There's a fear element as a cultural element." (P7)*

Some professionals provided views about specific chronic conditions among Roma people, e.g. high blood pressure, diabetes, overweight and obesity, managing long COVID symptoms and support to manage health. One professional felt there are many of these conditions affecting Roma people in Luton:

*"I think diabetes, overweight, mental health and, you know, depression are quite common with them [among the Roma community] because of their, you know, lifestyle and because of, you know, culture and diet as well. You know, so these are quite common." (P1)*

*"I would say [there are] many cases of non-compliance with medication, so they are going to have diabetes, hypertension, chronic*

*diseases, especially in the elderly category. But we have sometimes to keep our faith in making them understand why it's important to make lifestyle changes, and that alongside medication, they need to work on diet depending on certain conditions because, for example, the dietary changes in diabetes, hypertension or other diseases.” (P5)*

*“I remember being asked by one GP to go with a particular lady to a special diabetes clinic, some of the systems they set up for people who get the early stages of developing it. I went along with her and did my best to translate what was being said, but it was, to be honest, it was too technical for me to be able to translate and, and the rest of it. But the main point, you know, is you must change your lifestyle.” (P8)*

*“I think diabetes. I think generally it's things from my kind of experience working around the communities is my understanding is that when you come from countries where you've had very little access to things, suddenly when you come to a country and you've got these lovely sweets and Coca-Cola and things like that, then you're going to go to it [consume it], its lovely it tastes nice. So, I think healthcare [Roma people] is just not understanding what good healthcare is, because again, [they have] not always had access to the best nutrition. So, [they] don't know what good nutrition and diabetes is. So obviously, teeth is one that comes up a lot that children particularly have quite bad teeth again because are lots of sweets and then coke.” (P9)*

One said that Roma people did not share information about any chronic conditions:

*“I am not that much aware about this because this is subject [that contains] sensitive information. And if they don't provide this information to us, we cannot just ask them.” (P2)*

Another said that her clients with chronic conditions struggled with not knowing how to access repeat prescriptions:

*“My clients who are prescribed some medication for different diseases, like high blood pressure or diabetes, they don't know how to do the repeat prescription. They have to do the repeat prescriptions online. So, it's quite a difficult situation when someone is not told or not explained, they don't get any explanation how [it] is going to be. So, the doctor issued a prescription for prescription. They are going to the pharmacy, get the medication and that's all. And it's not followed up. It is not followed by the doctor, by the pharmacist, or by someone to tell them, to explain, to teach them. You know, you are in a foreign country. How do you know how the system is works? So, if you are not told, you will not know.” (P4)*

## *Chronic conditions*

Professionals explained that religion may underpin some of the healthcare issues around not wanting to be vaccinated or to engage in preventative healthcare.

*“...a the big group of people who we work with, they're Pentecostal Christians...And as I already mentioned about COVID, for example, they said God will save us. We don't want to be vaccinated... even [if] they [have] got serious illness issues with their [health], they just avoid to go to [the] doctor and they said [say], how long will I live [if I go] to [the] doctor and they say okay let God decide.” (P2)*

*“[They] believe that was the reason they were ill...perhaps a punishment from God.” (P8)*

*“So, you mentioned contraception, I think first. Yeah. Okay. So, the Roma people think this is true because all the families, they had a very deep belief sometimes coming from their religious convictions very often say they should have as many children as they can, starting as young as they can legally do [be].” (P8)*

*“If they [don't] want to go ahead with the pregnancy, they won't access that particular service because it is considered a cultural or religious sin.” (P5)*

*“I don't think we can change the religious part or the cultural part, ... if we know something cannot be changed then it's about addressing the current circumstances.” (P5)*

## **5.2 Suggestions for improving access to healthcare in Luton**

The main themes emerging from interviews with professionals for suggestions on improving access to healthcare for the Luton Roma community were: improve literacy on preventative healthcare, support with language, communication and digital technology, more cultural competency training for healthcare professionals and providers.

### **5.2.1 Improve literacy on preventative healthcare**

Professionals argued that engaging the Roma people to improve health literacy on prevention was imperative, and the responsibility of healthcare professionals. They explained that the Roma community seek help at the point of a medical emergency and this would ensure early intervention, and avoid the need for emergency care.

*“Like for the dentist they don't actually go to a dentist [to] treat their teeth, it is only when they have to extract one. So, it's not something [a service used] for prevention, [so education] I think is very important through schools.” (P4)*

*“Once they have a medical issue, they try to deal as soon as possible.” (P4)*

*“I don't see [a way to change] their attitude, they are living their life today and they are not thinking for tomorrow or for the future.” (P4)*

*“Sometimes they feel it is [a] wrong thing to discuss prevention, its more about treating the disease [than] preventing it and sometimes they feel we are making them understand prevention rather than treatment.” (P5)*

*“Making sure they understand why they are being chased, why we want them to come to their appointments, why we want them to come, why it's important to prevent, because at the end of the day the quality of life will be much better.” (P5)*

## 5.2.2 Improving knowledge of healthcare services in the UK, support with language and digital technology

Professionals felt that Roma people cannot manage to do well independently, for reasons of language, literacy, digital-skill levels, and a lack of experience around how healthcare systems work in the UK.

*“Because they don't understand the system.” (P9)*

*“Because when we go and talk about services, people don't really know a lot about them. So, with the maternity services, they obviously know they go in there to have their babies. But again, as I said, they don't know who does what, really. Like, you never get the sense that there was a great understanding of the system. But to be fair, it's really confusing. So, if you didn't speak English, [and] you were [are] new to this country, how would you know to access services? And it's so hard to access the NHS online system.” (P9)*

Professionals discussed the importance of supporting the Roma community with improving digital literacy.

*“...either they cannot book appointments at the GP, or if they are going, there is no support for them to get [what they need and advocate for themselves]. I mean once they have the appointment,*

*they have no translator, interpreter at the reception, [so] they cannot express themselves. They lose the appointment because if you don't tell the reception that you are there for the appointment, you don't know how to communicate this, then you lose the appointment which is booked for you.” (P4)*

*“And you need to [know] when you [get] pregnant to be referred, or [know how to] access a lot [of systems]... digital exclusion [is a problem] as well because we do so much online.”(P9)*

*“... Last week I had the case where people went to a GP practice... and they tried to get in to book [an] appointment. But they send [sent] them back and told them that they had to do it online... If somebody [makes you feel unwelcome] somehow this makes [it] hard to [raise and speak up about] prejudice [within] the system.”(P2)*

*“We use translators or we actually use people that speak another language. We have Romanian staff that call them to explain all the questions, sometimes we are successful, sometimes not, but then we try again.” (P5)*

*“They're responsible for communicating with GPs, [but] they can't, they are not able to do that not only because of the language... In general, it is most of the things like to book an appointment, you have to do it online or to call. Which for them is very difficult.” (P2)*

*“What challenges, the biggest challenges [are] communication. The second one, I would say, is the rejection they face. I would not call it discrimination. I wouldn't, I don't think it goes to that extent. But obviously [people] in those places [working in the healthcare services] do not understand anything about the Roma, and they simply have a very superficial understanding of this community group. And because of that, they treat them with no respect.” (P3)*

*“They simply do not know how to manage and navigate through the system of making an appointment or, you know, understanding where they should go and how should they speak, and what should they tell in order to get the service they need. So, they exclusively rely on us.” (P3)*

*“You know, when I talk about support, I don't talk about charity support. I'm talking about the service provider support. Why? So, the service providers [have] to find a way to interact with this community and understand their needs. ‘[They] should be also very much engaged with finding ways of improving its [their] own system so that it is accessible for everyone, not only for certain communities.” (P3)*

*“I have noticed so many of them unfortunately are not able to write or read. At the appointments, the main point of access now is the*

*eConsult [medical app] at the moment. In fact, this is one of the main forms of access to appointments, and unfortunately they cannot... [book] phone appointments. Many of them don't speak English therefore it won't be possible for them to book appointments, so then they try to come in and book [directly but are turned away, and told to book online].” (P5)*

*“Also, with access to perinatal care usually midwives don't make contact, but they always attend the appointments, but we also have problems with what happens after delivery. So, when they have health visitors, I still go to their house. They are not responding. We are concerned. And then when we try to find out, they don't answer the letters maybe because they can't read so there are huge problems.” (P5)*

5.2.3 Cultural competency training for healthcare professionals and providers  
Professionals unanimously discussed the need for cultural competency training for professionals and providers, to manage the perceived discrimination experienced by the Roma community when accessing healthcare services in Luton.

*“I think medical professionals should understand more about the Roma [community], about their culture, understand the difference...[within the community]. Obviously, communication is very important. That would help a lot. [We need] people, you know, within the medical profession who are more tolerant and more sensitive to the vulnerabilities of [Roma] people, more dedicated staff rather than someone who rejects [them]. From the first moment you start talking [to the moment they send] you home. So yeah, I think more dedicated staff is really critical.” (P3)*

*“Wouldn't it be wonderful if you had all these organisations regularly coming to Luton Roma Trust so the Roma people can come in and talk to them?” (P9)*

*“Cultural awareness is a massive one. We need to understand [the] communities and [their] differences and celebrate them so we can actually properly support them. That's a huge one... cultural awareness, as well as knowing [that] they have an increased risk with their predisposition to different health conditions.” (P7)*

*“I really believe that having a better understanding of the Roma community's needs is really critical for the medical people here within the hospital and GP services.” (P3)*

*“[It's] a bit difficult for us to separate the Romanians from the Roma community because many of them, when they register, they select Romanians, not Roma population.” (P5)*



*“So, we're looking to change that with these workshops, by taking professionals out to these groups and giving them accessible information. It's no point just translating things on the spot and giving out translated leaflets. They have to contain that information to have a follow-up appointment. So, we're working on how to build a bigger picture of accessible workshops where they can get as much information as possible in a way that they can carry on accessing it.” (P6)*

*“So, I know, and I understand people who do not have a certain level of education. They cannot manage their anger. They cannot express themselves. So probably this is an issue for the staff when we are working with different people, when [the] council or NHS or police or GP or whoever is employed working with different backgrounds, different people, you might have to know the culture of that community and then approach them because they are the way they are. So, it's not that the person is against you or is having some issues with [you] personally. It's about how they are in general. So, if you don't know their culture, you certainly will say he is rude, but actually he's not rude is the way they express themselves. And yeah, even me working with them, I sometimes [experience] this. [My initial] approach [is] trying to calm them, and I just realise, oh, they cannot be calmed in the moment.” (P4)*

*“Awareness training or something like this about the culture of and the behaviour of Roma community [is crucial].” (P4)*

*“Information. Yes, I think that would be very useful indeed for the medical professionals, [and] for the doctors to have a sort of material that they could read about the Roma, and especially about taboo topics that they should be aware of if the Roma person comes in.” (P3)*

*“I think the NHS and the medical system in general would benefit from having materials or discussions with partner organisations, who could come and deliver Roma cultural awareness training... so, what's the point [in having] a system in place which doesn't work in an effective way, doesn't work in the same way for everyone? Right. It results in discrimination, at least. You know, it is a type of discrimination, and it needs to be improved.” (P3)*

*“The cultural differences in Romania [are vast]. You don't have a midwife you have [a] doctor and what they say is Law, you believe what the doctor says, in terms of birth choices, birth rights.” (P6)*

*“First of all [the healthcare services should] train their staff to raise awareness of [the] Roma [community].” (P1)*

*“Though as I say a lot of [the] anxiety [is] because of the language [and] cultural barrier. Not understanding how the whole system works in the UK. There are cultural issues that make it [hard to] approach [and] access health services. Some are tricky and difficult if you've got a very different world view. Also, [it's] perhaps important to say that the Roma people generally have a much shorter life expectancy,*

*partly because of their lifestyle and conditions of life, and partly possibly because of what we call 'consanguinity'. So that [is an important] distinction."* (P8)

*"It does happen many times that the people at the reception talk very rudely, and they simply don't try to improve the service for everyone in an equal way."* (P1)

*"So, the GP service I think needs to be improved in certain areas to provide services for Roma communities."* (P4)

*"They are a very different community than other Eastern European communities. Roma is totally different. Roma is the only community of them all [that is] almost like an enslaved community which has been absolutely abused. And when you mention any official [legal professionals], that's a threat to them. So, they're used to being treated and abused. So, if a police officer or a health officer, you mention these are the people who abused them. So, to them, these professionals are a threat."* (P1)

*"Really, they are the most discriminated against minority group in Europe. And because of all these vulnerabilities, you know, it's simply very, very hard to make it, you know, in a way that would work."* (P3)

*"They don't even know how to use Google Translate... They don't read their own language. So, it is certainly a disadvantaged population."* (P4)

*"He was sent to the A&E for the investigation, but he had an appointment. So, he missed the appointment because the receptionist had sent him to the A&E."* (P4)

*"All the services need to have a very good understanding of the culture ...and be aware of the specific needs of these groups. Otherwise, they won't be able to treat them effectively."* (P3)

*"So, we're going to bring an element of wellbeing because a big issue for the Roma committee [community] is their diet and their [un]healthy lifestyles. There's a big risk of diabetes in the community. So, we're bringing in dietitians, we're going to bring in access to like leisure centres with some subsidised antenatal classes."* (P6)

Professionals explained that as a result of negative experiences within healthcare the Roma community may become disengaged.

*"Sometimes [Roma people get] de-registered. Some of them were de-registered and [when we ask why] they [the healthcare services] say because they were not [attend]]."* (P4)

*"There is sometimes an issue with getting seen by the doctors in the UK or the hospitals. I heard about it anecdotally, I never witnessed it myself. But some Roma were told the surgery is full and they wouldn't*

*register them. Another issue that occurred a lot was that a family would go away for a bit, maybe go back home, maybe for medical reasons, go home. They would go home for lots of different reasons: a funeral, you know, or renewal of a passport or something like that. And when they came back [they found] they'd been struck off the doctor's list." (P8)*

*"Yeah, and it's very difficult to calm a person who is not having or was not treated equally. So, this is like a cycle. He's feeling frustrated the client and then shouting to the receptionist or to the doctor and trying to get the client to be calm. It's quite difficult. After he waited for so long. And sometimes I think this is the image created by the Roma community for NHS staff. Oh, they are coming here all the time shouting and having this attitude to us but it's not a shout either." (P4)*

*"Clients get annoyed and frustrated. [They] try to explain and get more upset and express themselves with a high voice and then the receptionist or who [ever] was on the [end of the phone] or face-to-face said [tell them to] calm down. But the client couldn't calm down because he was not understood. He tried to explain more and more what happened and the receptionist couldn't accept that the client had a raised voice." (P4)*

#### *Suggestions for the best ways to provide cultural competency training for healthcare professionals and providers*

Professionals gave suggestions for the best way to provide cultural competency training for healthcare professionals and providers. These included training professionals to understand that UK services do not make sense to Roma people, and training professionals and others to coach Roma people on how to ask for what is needed during a health appointment, in English language. These suggestions are crucial in community conversations to build trust with the Roma community.

#### Training professionals to understand the needs of the Roma community and coaching the Roma community to enable them to ask for what they need

For example, professionals should understand that the concept of, for example, preventative healthcare or counselling for mental health problems are not discussed due to the stigma associated with chronic conditions and mental illness:

*"What is the counselling, [and] what is that for? So [on the] emotional side, when someone is depressed in their community, their*

*background is not something which you can deal with as a professional.” (P4)*

*“One of the issues with mental health was that in the Roma language, they don't speak and they don't have special vocabulary for issues of mental health. They don't. They don't have words in their Romani dialect for depression.” (P8)*

*“Mental health is not spoken about... [it's] seen as shameful [so they] covering things up and not disclosing it because there's a fear... There's this thing when the shame that this mother is coping. So, professionals just have to think that their language and terminology does not create fear and worry. But I think mental health is a massive area of concern... Roma women as well, it's the same thing within the culture. They just don't discuss it...” (P7)*

*“Another [challenge is surgeries. To get appointments, you have to understand what's being offered.. And I think a part of that is the cultural awareness from the GP's and the access to what's available.” (P6)*

*“If they need to wait and they feel it's not something they should wait for then the unhappiness will arise, and it can be difficult to explain why, especially for our receptionist and the front-line person dealing with it. For example, in your home country it's very easy to book an appointment for the same day, but here because the demand is not as high, it is not. And if we explain you have to wait one or two weeks because it's a routine problem what you are saying is very unfair. It's about explaining that it's not only you, but everyone also has to wait if it's a chronic problem... They think [don't understand] why [they can't be seen] on the same day. It's the process of explaining and making sure they understand how are things here [work]... those are the rules it's not that you are being racists.” (P5)*

*“The staff are doing their best, but they can't cover everything. Adding on top of that, [is] the need to have cultural awareness and [awareness around] language differences.” (P7)*

Another suggestion made was for professionals to create English language courses for Roma people, to support their access to services. The courses could cover common questions and basic vocabulary that would help them to make an appointment, and describe a medical concern.

#### Community engagement to build trust with the Roma community

Professionals mentioned the importance of conversation within the Roma community as a way of building trust, which is an essential prerequisite for improved levels of satisfaction with healthcare services and professionals.

*“So, there's a trust thing.” (P1)*

*“Sometimes they don't trust the professional... they don't trust the professionals 100 per cent when it comes to prevention...(P5)*

*“And I think professionals aren't aware of that and the discrimination that Roma people have faced. And therefore some people find it quite challenging to engage with services, particularly authority figures, because there's a fear [and] mistrust... It's a collaboration and you know, everything should be a collaboration with community groups, in particular [the] Roma [people] if you are looking to gain trust.” (P9)*

*“They don't access care as readily as say some other community groups, and the work that we have staff to do and will continue to do is really highlighting that they don't trust us.” (P6)*

*“We wanted to talk about health in general. I think that's in general and that's what we have to be patient with to rebuild that trust on some levels. But it's a slow process... Trust is massive and I think they've historically been let down so much by professionals, [their needs have been] overlooked, not listened to [and] stereotyped [which is] very unhelpful”(P7)*

*“And the biggest change you can make is building trust.” (P7)*

*“And building up. I think this is key. Building up trusting relationships over time.” (P8)*

Professionals mentioned that one route for community engagement was through informal contact, organised fairs, churches and schools. Professionals explained the importance of timely engagement/conversation, for example, at the point of pregnancy for safeguarding issues and early intervention.

Organising community activities, such as health fairs, have been reported as helpful in building trust and engagement with the Roma community.

*“Organising [a] health fair is an informal way, to get into, you know, people's heart and mind.” (P1)*

*“I think that with this community, if you actually visit people in their homes, they will open up in a way that they would never do outside.” (P8)*

*“And there were a lot of children that probably should have been at school that weren't at school. So yeah, this is getting to know a*

*community and then you can engage better. That is the only way you're going to make services better.” (P9)*

*“I think it's just building trust with the community. I think that's definitely one thing I've learned over many years, that if you go into the Roma community, if you go to church services, if you go to community centres where the Roma community are regularly meeting, and you go in and spend time and get to know people and talk about services and explain what services do and how they work, then people will access them. It's trust and time and I think that is huge... So, my feeling is always that we need to be more present in the community and then we'll develop better relationships.” (P9)*

*“You need to build trust and therefore be present, getting to know people is really, really important.” (P9)*

*“So, it's a long process to build up trust, but this has to be changed from the villages down to the system, the way things operate.” (P7)*

*“So, there are days that they are quite well attended in the churches. So, there's, you know, there's big numbers of girls in the church. But church is a faith place, not a health zone. So, you know, that's not being [utilised effectively]. So that could be something worth considering and getting the churches more involved in this and getting the message through them.” (P1)*

*“Children from [the] Roma community are at school...so [giving information through] schools, through parent evenings.” (P4)*

*“This community, they're going to be here forever. They're likely to be like the other migrants if they're going to be here... So, you've got to think about early interventions.”(P1)*

*“Also, there are community events, for example, next week we have an event with the fire services where we mention about the services available in the community and we try to make those events regularly.” (P5)*

*“Explaining how things work here, which we are trying to do, but we are only one place and there are multiple practices in Luton along with the population and those events should be made accessible to them... by advertising posters in the community and places where they go.” (P5)*

*“It's just sort of about making sure that they feel welcome... I think from my point of view, a massive part of our focus is reaching out to our communities and not the hard-to-reach [ones], but the ones that aren't listened to [and] that are used to being overlooked, not heard.” (P6)*

### Roma community workers and healthcare professionals

Professionals discussed the importance of gender appropriate Roma community workers to engage with the Roma community to provide healthcare information and address sensitive issues.

*“So, first of all, if you are trying to engage a Roma woman and if you send a man, you are going to fail because every man that they met is an abuser to them.” (P1)*

Some professionals discussed the importance of female community workers for pregnant Roma women:

*“A Roma woman would not want to be seen by a man... I was often the only person available to do that, they didn't mind that I was a man... But just to say generally, the women would want to see a female doctor as much as possible.” (P8)*

*“Well, as I say, having Roma women champions [is important], okay, people that work in groups that would go to their homes.” (P8)*

*“And one key cultural factor is that Roma women do not like speaking about health matters when there are men around.” (P8)*

*“But it's almost like the younger women will go to the older women in the community to ask about things, and they're trusting the elders about healthcare advice... Yeah, but [when you] build that support and build that trust then they think actually you're helping us. We will bring our pregnant women to you because we know that they'll get the care that they need.” (P7)*

*“So [when that] happens, a trust is built and then the woman is comfortable in getting out of her cultural quarter and [coming] for help because by then she has [received help from] a nurse or a what you call midwife or a family worker and got good things.” (P1)*

*“When the woman is pregnant, they're likely to seek help. They're likely to seek support because they're vulnerable then.” (P1)*

*“But if you don't know anything about the service that midwives provide your starting point would be the GP. But if you are not able to access your GP surgery, then that ends it there. And that's why we have many women who are accessing the services when they are at the very least [last] stage, a very advanced stage, of their pregnancy. And if they get to that point and they are in the system, they, you know, they miss their midwife appointments because the midwife doesn't speak Romanian or Roma.” (P3)*

Another important point was the need for more Roma people represented in the healthcare workforce and the importance of community workers from the Roma community:

*“Seeing more Roma people in the health healthcare system because right now they don't see Roma, they don't see their people.” (P1)*

*“I think hiring Roma staff, hiring Roma medical professionals would be very supportive.” (P3)*

*“It's really communication and engagement and offering them opportunities in different sectors so they become comfortable and confident.” (P1)*

*“So it's better to make a long-term investment in, you know, helping their communities to train their own people and not rely on somebody else to do the job for them.” (P1)*

*“I think [it would be beneficial] to have employees in their system who speaks their language.” (P4)*

*“Try finding the people that speak their language inside the main project that can address them to discuss it and their needs.” (P5)*

Roma people may prefer to work with other Roma people, to build trust:

*“So, where we come from, we were the slaves and the slave masters. So, to them we're still afraid too... you have to understand the deep-rooted issues that exist... So, someone, if you employ a Romanian, thinking that that's going to solve your problem, to work with Roma, that's not going to work. So, you would need a Roma to work with the Roma.” (P1)*



## 6.0 THE IMPLICATIONS OF THE PROJECT FINDINGS AND FUTURE ACTIONS

This final section of the report summarises what the Luton Roma community and professionals who work with them said, as well as their solutions/enablers and our recommendations to improve access to healthcare and tackle inequalities in health.

<b>They said</b>	<b>Their solutions/enablers and our recommendations</b>
<p>We do not know about healthcare services or referral routes.</p>	<p>Increase information on available healthcare services and referral routes.</p> <p>Improve health literacy on preventative healthcare services, health and wellbeing and chronic conditions.</p> <p>Recruit and train community members as health and wellbeing champions to transfer knowledge and information.</p> <p>For all of the above:</p> <ul style="list-style-type: none"><li>• use face-to-face discussions conducted in Romanian or other languages they understand at Roma Community Centres.</li></ul>
<p>We have difficulty accessing GP appointments because of:</p> <ul style="list-style-type: none"><li>• unacceptable waiting times.</li><li>• language and communication barriers, and the limited availability of translators.</li><li>• poor literacy and digital abilities.</li></ul>	<p>Increase language and communication support for the Roma community, by using:</p> <ul style="list-style-type: none"><li>• videos.</li><li>• written information in the form of leaflets or the internet.</li><li>• a telephone translator to help with booking the appointment times.</li><li>• all information in Romanian and other languages they understand</li></ul> <p>If devices are given to people to request health appointments or a translator:</p>

	<ul style="list-style-type: none"> <li>ensure all digital devices in health centres include the option for Romanian or other languages they understand to be selected.</li> </ul>
We don't like being called Gipsy/Gypsy and Traveller. We like being called Roma.	<p>Raise awareness about preferred word being Roma and reduce use of Gipsy/Gypsy and Traveller in common parlance, as well as forms recording ethnicity.</p> <ul style="list-style-type: none"> <li>ask that healthcare professionals and other organisations, refrain from using the term 'gipsies' or 'gypsies' or 'travellers' to refer to the Roma population, as this term is perceived as derogatory/discriminatory by this community.</li> <li>ensure healthcare services include a diversity tick box for 'Roma'.</li> </ul>
We feel discriminated by healthcare professionals.	<p>Cultural competency training for professionals, which should include training for professionals on how to better support Roma people in relation to:</p> <ul style="list-style-type: none"> <li>their lack of experiences in preventative healthcare vs. emergency healthcare.</li> <li>no experience of using contraception or vaccinations 'back home'.</li> <li>managing stereotypes about additional vulnerabilities e.g. sex trafficking and sex work.</li> </ul> <p>Build trust by reaching out to the Roma community in these settings:</p> <ul style="list-style-type: none"> <li>informal settings</li> </ul>

	<ul style="list-style-type: none"> <li>• families at schools and education settings</li> <li>• engaging families at the point of pregnancy</li> <li>• consider churches to build trust with the Roma community.</li> </ul>
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## 7.0 CONCLUSION AND NEXT STEPS

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This report presents the views of the Luton Roma community, and professionals who work with them, on accessing healthcare in Luton and co-producing solutions. The main healthcare conditions causing concern for the Roma community were maternity and child healthcare, and adult healthcare. Participants did not discuss chronic health conditions, such as diabetes and obesity, which we specifically asked about. Our participants were most likely to access GP surgeries and emergency services. Overall participants were dissatisfied with their experiences of using healthcare services in Luton.

We identified many barriers which included limited knowledge about the range and referral routes to healthcare services in Luton, long waiting times and quality of care which resulted in decisions to return to Romania for healthcare. Language and communication problems were a significant barrier and resulted in difficulties and delays in setting up health appointments, delays in being seen, as well as difficulties in communication during appointments. Perceived discrimination from service providers was spoken about in relation to being treated differently or less favourably on the grounds of being Roma, not speaking English, and being called 'gipsy' or 'gypsy' which the community consider unacceptable. Research has argued that the identifiers of 'gipsy' or 'gypsy' are the 'last acceptable prejudice in Europe', and that anti Gypsyism is an unacceptable obstacle to the inclusion of the Roma community because it leads to stereotypes about the Roma culture.<sup>14</sup>

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<sup>14</sup> Kende, Anna, Márton Hadarics, Sára Bigazzi, Mihaela Boza, Jonas R. Kunst, Nóra Anna Lantos, Barbara Lášticová, Anca Minescu, Monica Pivetti, and Ana Urbiola. "The last acceptable prejudice in Europe? Anti-Gypsyism as the obstacle to Roma inclusion." *Group Processes & Intergroup Relations* 24, no. 3 (2021): 388-410.

Our findings are similar to other UK research studies. A project with the Roma community in Leeds concluded that the poor health outcomes of Roma people was closely linked to language barriers, which prevented accessing healthcare and healthcare messages, as well as the wider social determinants including housing, employment opportunities and money.<sup>15</sup> Research with the Roma people in Europe also highlights the poor health outcomes experienced by Roma people compared to majority populations. Poor health outcomes have been associated with the marginalisation and exclusion of the Roma people, and the problems that occur when accessing healthcare.<sup>16</sup> A systematic review of 'Gypsy', Roma and 'traveller' access and engagement with health services, reviewed ninety-nine studies from 32 countries and reported barriers to health service usage were related to organisation of health systems, discrimination, culture, language, health literacy, service-user attributes and economic barriers.<sup>17</sup> A study with the Roma people in Spain, argued that barriers could be summarised under two categories which were existing institutional arrangements and interaction with health professionals.<sup>18</sup>

Professionals who work with the Roma community echoed the sentiments of the Roma community with added concerns about additional vulnerabilities, which included sexual exploitation, contraception services and contraception use, poor uptake of vaccinations, and limited understanding of chronic conditions. The poor uptake of vaccinations relating to measles, mumps and rubella (MMR) immunisation has been documented and attributed to access to healthcare services, in addition to culture, perceptions of risk, and engaging with healthcare staff.<sup>19</sup>

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<sup>15</sup>Warwick-Booth, Louise, Joanne Trigwell, Karina Kinsella, Kathryn Jeffreys, Derek Sankar, and Marketa Dolezalova. "Health within the Leeds migrant Roma community; an exploration of health Status and needs within one UK area." *Health* 9 (2017): 669-684.

<sup>16</sup> Kirwan, G. and Jacob, D., 2016. Addressing barriers to healthcare access for Roma: A community development approach. *Administration*, 64(2), pp.157-177.

<sup>17</sup> McFadden, Alison, Lindsay Siebelt, Anna Gavine, Karl Atkin, Kerry Bell, Nicola Innes, Helen Jones, Cath Jackson, Haggi Haggi, and Steve MacGillivray. "Gypsy, Roma and Traveller access to and engagement with health services: a systematic review." *The European Journal of Public Health* 28, no. 1 (2018): 74-81.

<sup>18</sup> Aiello, E., Flecha, A. and Serradell, O., 2018. Exploring the barriers: A qualitative study about the experiences of mid-SES Roma navigating the Spanish healthcare system. *International journal of environmental research and public health*, 15(2), p.377.

<sup>19</sup> Smith, David, and Paul Newton. "Structural barriers to measles, mumps and rubella (MMR) immunisation uptake in Gypsy, Roma and Traveller communities in the United Kingdom." *Critical Public Health* 27, no. 2 (2017): 238-2

Discussion with the Roma community and professionals who work with them highlighted the importance of increasing information on the available healthcare services and referral routes, improving health literacy on preventative healthcare services, health and wellbeing, and chronic conditions, recruiting and training community members as health and wellbeing champions to transfer knowledge and information, increasing language and communication support for the Roma community, raising awareness about the preferred identifier being Roma and not 'gipsies' or 'gypsies' or 'travellers', and cultural competency training for professionals.

The findings from our research provide an action framework for the BLMK ICB decision makers to put in place inclusive interventions (prevention and health promotion activities/events) that acknowledge and address the barriers impacting on the Roma community when accessing healthcare. These interventions should be facilitated using the community connector model to build a culturally nuanced and trusting collaboration between the Roma people and service, to reduce inequalities and improve health outcomes.



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