



Talk, Listen, Change (TLC)

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



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Background

One of the largest concentrations of the Roma community is in Luton, Europe.¹

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.²

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.³ The existing evidence base highlights that there are gaps in cultural competence and knowledge regarding the Roma community in the UK, which can leave shortfalls in the provision of services with negative effects on health.⁴

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.

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. 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 this project provides in-depth contextualised findings and co-produced solutions to ensure services meet the needs of the Luton Roma community.



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

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

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

4 Greenfields, Margaret. "Good practice in working with Gypsy, Traveller and Roma communities." *Primary Health Care* 27, no. 10 (2017): 24-29.

The community engagement approach

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.

Researchers have recorded the challenge of engaging the Roma people in research.⁵ We used our Talk, Listen, Change (TLC) approach⁶ 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 their views on accessing healthcare services in Luton. Therefore our research also provides methodological insights on the value of engaging with communities for making organisational change.⁷

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.⁸ The self-identity of the Roma community has been homogenised⁹ 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.¹⁰

5 Condon, Louise, Helen Bedford, Lana Ireland, Susan Kerr, Julie Mytton, Zoe Richardson, and Cath Jackson. "Engaging gypsy, Roma, and Traveller communities in research: Maximizing opportunities and overcoming challenges." *Qualitative Health Research* 29, no. 9 (2019): 1324-1333.

6 https://m.luton.gov.uk/Page/Show/Health_and_social_care/coronavirus/Pages/talk-listen-change-executive-summary.aspx

7 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) 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".

8 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.

9 Csepeli, 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.

10 <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 Luton¹¹ based on the Office of National Statistics (ONS) ethnic categories,¹² but also recruited based on self-ascribed identity e.g. individuals who identify as Roma.

A purposive¹³ 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. 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.



Are you from a Roma or mixed heritage ethnic background and live in Luton?

If so, we are interested in your views and experiences about using healthcare services and how we can improve support to meet your health needs in Luton

Give us your views by:

- **attending a focus group** – register your interest with Ioana Nicolae Monica by calling 07404 985317
- **taking part in an interview** if you are a health or social care worker and working with the Roma community




11 https://m.luton.gov.uk/Page/Show/Community_and_living/Luton%20observatory%20census%20statistics%20and%20mapping/population/Pages/2021-Census-population-figures.aspx


12 <https://www.ons.gov.uk/peoplepopulationandcommunity/cultural-identity/ethnicity>

13 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 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.



The focus group discussions and interviews were carried out using a semi-structured discussion guide.¹⁴

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.
- 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.

¹⁴ 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

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.¹⁵ The interviews were

¹⁵ 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.

carried out in English and transcribed by an 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.

A thematic Framework Analysis approach was used to analyse the data.¹⁶ 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 meet the objectives of this study.

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 saturation¹⁷ 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.

16 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.

17 The principle of saturation in qualitative research is when the same themes repeat themselves. In other words no new information is emerging from discussions. For further information please see Saunders, Benjamin, Julius Sim, Tom Kingstone, Shula Baker, Jackie Waterfield, Bernadette Bartlam, Heather Burroughs, and Clare Jinks. "Saturation in qualitative research: exploring its conceptualization and operationalization." *Quality & quantity* 52 (2018): 1893-1907..

What did we do?

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



Where and when?

Data collection took place 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.



Supporting details

Ethical approval was obtained from the University of Bedfordshire (UoB) Ethics Committee.



The implications of the project findings and future actions

This table 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.

 They said	 Their solutions/enablers and our recommendations
<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"> • use face-to-face discussions conducted in Romanian or other languages they understand at Roma Community Centres.
<p>We have difficulty accessing GP appointments because of:</p> <ul style="list-style-type: none"> • unacceptable waiting times. • language and communication barriers, and the limited availability of translators. • poor literacy and digital abilities. 	<p>Increase language and communication support for the Roma community, by using:</p> <ul style="list-style-type: none"> • videos. • written information in the form of leaflets or the internet. • a telephone translator to help with booking the appointment times. • All information in Romanian and other languages they understand. <p>If devices are given to people to request health appointments or a translator:</p> <ul style="list-style-type: none"> • ensure all digital devices in health centres include the option for Romanian or other languages they understand to be selected.
<p>We don't like being called Gipsy/Gypsy and Traveller. We like being called Roma.</p>	<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"> • 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. • ensure healthcare services include a diversity tick box for 'Roma'.
<p>We feel discriminated by healthcare professionals.</p>	<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"> • their lack of experiences in preventative healthcare vs. emergency healthcare. • no experience of using contraception or vaccinations 'back home'. • services in Luton may not match those available 'back home' e.g. counselling. • managing stereotypes about additional vulnerabilities e.g. sex trafficking and sex work. <p>Build trust by reaching out to the Roma community in these settings:</p> <ul style="list-style-type: none"> • informal settings and including organised fairs • families at schools and education settings • engaging families at the point of pregnancy • consider churches to build trust with the Roma community.

The findings

Views of the Roma community

• 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 Roma people were treated less favourably compared to other ethnic groups. This was a cause of concern.

My children, they had rashes, and I was told [it was] nothing, I just must wait for it 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)

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.
- 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 not being 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.

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)

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

- Very limited understanding about referral routes resulting in attending emergency services rather than early help-seeking at preventative services.

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

- 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.

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)

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.

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+)

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)

- 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.

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)

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+)

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)

Perceived discrimination from service providers.

- Almost all participants reported feeling they were treated differently and less favourably, on the grounds of 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)

- Participants said they preferred to be called Roma, and not 'gypsy' or 'gipsy' which they consider insulting and 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.

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)

- 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.

The lady at the reception noticed that I was a Roma person and I noticed that she immediately changed her look.

(Female, aged 56+)

- 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, referral routes to and location of healthcare services. Information should be provided in Romanian.

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)

- 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 understand.

It would help me if there was information available in Romani and not just in English.

(Male, aged 20-25)

It would be helpful if we could get information about health services in Luton through leaflets, but in Romanian.

(Female, aged 20-25)

I think that information about health services in Luton should be provided through videos and leaflets in Romanian.

(Male, aged 20-25)

The internet helps us, a lot.

(Female, aged 20-25)

Tackling issues of language and communication including the lack of availability of translators.

- There was a consensus about the need for 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.

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)

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.



Views of the professionals who work with the Roma community

• 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.

Unless someone would take them through the referral process and we sit next to them and help them fill it in, 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)

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

(P9)

They would not know where to go for the appointments.

(P4)

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.

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. [The environment is] isolating, not supportive, not trusting.

(P7)

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.

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)

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

(P3)

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)

- 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.

People consider that they are not treated equally.

(P4)

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.

(P4)

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 contraception services, vaccinations and chronic conditions.

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)

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)

- 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.

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)

[They] believe that was the reason they were ill – perhaps a punishment from God.

(P8)

- **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.

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)

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)

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)

- Professionals felt that Roma people cannot manage to access to healthcare independently, for reasons of language fluency, poor digital skills and a lack of experience about how healthcare systems work in the UK.

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)

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)

• Cultural competency training for professions

- 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.

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)

Awareness training or something like this about the culture of and the behaviour of Roma community [is crucial].

(P4)

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)

- 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 conversations to build trust with the Roma community.



Conclusion and next steps

This report presents the views of the Luton Roma community, and professionals who work with them, on accessing healthcare services 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 to accessing healthcare services 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.¹⁸

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.¹⁹ 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.²⁰ A systematic review of 'Gypsy', Roma and

'traveller' access and engagement with health services, which included ninety-nine studies from 32 countries, reported barriers to health service usage were related to the organisation of health systems, discrimination, culture, language, health literacy, service-user attributes and economic barriers.²¹ 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.²²

Professionals who work with Roma people 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.²³

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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