



Your Voice Counts St Thomas Gypsy and Traveller Community

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Introduction

A recent outbreak of measles in the St Thomas' English Gypsy and Irish Traveller community, identified that many children were not vaccinated in June 2024, which led to intervention and children being vaccinated. During this process, it was noted that the Luton Gypsy and Traveller community had identified some concerns and barriers to accessing healthcare services. HWL was approached by Luton Borough Council (LBC) to engage with the community and gather their views on access to health and social care.

Healthwatch Luton (HWL) would like to thank the Luton Irish Forum, who introduced HWL to the community, joined HWL on the first two visits, and assisted HWL in engaging in a dialogue with the community about their experiences in relation to access to healthcare services and co-producing solutions.

This report presents evidence gathered through informal interviews with individuals from the Gypsy and Traveller community. Information collected by Healthwatch Luton shows that the community mistrusts authorities and faces multiple barriers to accessing healthcare services. Healthwatch Luton worked with the Primary Care Network to improve cultural awareness, overcome these barriers, and identify how services can be developed to meet the needs of this community.

Information gathered will be fed back to the Integrated Care Board and Luton Borough Council to identify where services can be provided to meet the needs of the Gypsy and Traveller community. Any data collected from individuals and the community will be stored within our intelligence system in a pseudonymised or anonymised format and will only be shared in a completely anonymised format.

Healthwatch Luton will use this data as part of the project for Public Health Luton and to contribute to the wider picture of intelligence within services in Luton. Healthwatch Luton will ensure that all individuals are informed about what their data will be used for and how it will be used.

Aim:

HWL aims to engage in a dialogue with the Luton Gypsy and Traveller community in St Thomas' and with professionals from the primary care services within Stopsley, whose services they use, to improve understanding of their views on accessing services and to better understand the barriers they experience when accessing healthcare.

The goal is to co-develop solutions to improve access to services and experiences, in collaboration with the Integrated Care Board, Luton Borough Council, local Primary Care Networks, and primary care services through co-production. Additionally, the aim is to identify ways to improve cultural awareness and services for this community.

Objectives:

- HWL will visit the Gypsy and Traveller community and engage in dialogue and discussions with individuals and families about their experiences using healthcare services, with the aim of identifying any barriers to accessing services.
- HWL will engage in dialogue with professionals working in primary care services in Stopsley, providing feedback on service users' concerns and discussing ways to improve access to healthcare and services for this community.
- To better understand the needs of the Gypsy and Traveller community and enhance cultural competency, in order to build relationships and co-produce approaches that improve the experience and health of the community.

Methodology

Healthwatch Luton, in collaboration with the Luton Irish Forum, visited the St Thomas' community in Stopsley to capture the views of Gypsy and Traveller community service users. After being introduced to the community by the Luton Irish Forum, Healthwatch Luton (HWL) was able to speak to and listen to individuals in confidence, ensuring that all feedback

was kept in an anonymous format, which helped to build trust. This approach aligns with the HWL mission: *'To make sure people's experiences help make health and care better.'* And the HWL values:

- Listening to people and making sure their voices are heard.
- Including everyone in the conversation –especially those who don't always have their voice heard.
- Analysing different people's experiences to learn how to improve care.
- Acting on feedback and driving change.
- Partnering with care providers, Government, and the voluntary sector – serving as the public's independent advocate

Data collection was carried out through informal interviews, which took place face-to-face on four occasions at St Thomas' and at a Christmas Party at St. Mary's Church Dunstable. The data collection occurred during August, September, October and December 2024. HWL spoke with twelve residents from the site—ten females and two males—who shared information about their own experiences as well as those of their close family members living with them. Although the sample size was small, it represented approximately a third of the Stopsley community.

The sample group consists of families residing in a community-oriented environment, including a mix of parents with young children and multi-generational families. The group is specifically made up of Irish Travellers and English Gypsies, with the sample of adults ranging from young adults to older individuals. Residents may have varying degrees of familiarity with the local healthcare system, from long-term residents to newcomers who are more reliant on public healthcare services. The healthcare needs within this group are likely to focus on general family health, child care, maternal support, and access to emergency services.

During the initial two visits, a representative from the Luton Irish Forum assisted with the interviews and facilitated engagement in dialogue. On one of these visits, the practice manager from the e Quality, Primary Care Network accompanied Healthwatch Luton (HWL) and provided guidance on service access and appointment scheduling. The interviews were conducted informally, with residents leading the discussions. A

conversation guide was used minimally to help direct the conversation, but no formal questionnaire or pre-determined questions were used. The majority of the feedback gathered focused on primary care services, particularly the local General Practitioners (GPs), although some comments were also made regarding local hospital care.

A thematic framework analysis approach was used to analyse the data. This process involved gathering the data, thoroughly familiarising ourselves with the content and identifying key themes.

Executive Summary

Purpose

Healthwatch Luton was commissioned by Luton Borough Council to gather the views of the local Gypsy and Traveller community. To ensure the experiences of this community when accessing local health services were captured, four visits were made to the St Thomas' site. These visits provided residents with the opportunity to share their experiences of using both primary and secondary health services.

During the interviews, a wealth of feedback was collected regarding the residents' personal experiences, as well as those of their families, in accessing local services. This included both primary and secondary care, alongside the barriers they had encountered.

Background Research

National research by Families, Friends and Travellers (2022) identifies key health inequalities affecting the Traveller community:

- Traveller people face life expectancies that are between ten and 25 years shorter than the general population.
- Traveller people experience significantly higher rates of long-term illness, health problems, or disabilities, which limit daily activities or work.
- The health of a Traveller person in their 60s is comparable to that of an average White British person in their 80s.
- An All-Ireland study found that suicide rates are six times higher for Irish Traveller women than for women in the general population, and seven times higher for Traveller men.

Barriers to accessing healthcare include a lack of trust in services, primarily due to fears of discrimination, as well as digital exclusion.

Following a measles outbreak at the St Thomas' site in Stopsley, feedback from the community to Luton Public Health highlighted several pressing health issues, including ten deaths linked to cancer (notably a high prevalence of bowel cancer, often diagnosed too late) and a high rate of suicide. This feedback underscored the urgent need for enhanced screening, medical intervention, and mental health support.

The community also reported a perceived discrimination within healthcare services, with many residents feeling unfairly treated or judged because of their background. This perception of discrimination has contributed to a lack of confidence in healthcare providers and institutions, further discouraging residents from engaging with the healthcare system. Many residents believed that once diagnosed with a serious illness, recovery was unlikely, which deterred them from seeking preventative or early medical intervention. Medical help was typically only sought when health issues had become severe.

There is a significant opportunity for health promotion in addressing these issues. Residents on the site also face additional challenges when accessing healthcare, including childcare and transport barriers.

Key findings

Introduction

This report presents the findings from Healthwatch Luton's engagement with the Gypsy and Traveller community at the St Thomas' site in Stopsley, Luton, regarding their experiences with local healthcare services. Twelve residents (ten women and two men) participated in informal interviews, which were conducted in collaboration with the Luton Irish Forum. They shared their own experiences, as well as those of their close family members living on the St Thomas' site in Stopsley.

While the report highlights several challenges faced by the community in accessing healthcare, it also includes positive feedback and experiences, which offer valuable insights into what is working well. These positive

themes help to identify areas of good practice that could be expanded or replicated, contributing to the development of more inclusive healthcare services for all.

Key Findings

Positive Feedback on Healthcare Services

Despite the challenges reported by many, some residents shared positive experiences regarding the care and service they received:

- Male Resident I, who had recently completed cancer treatment, expressed satisfaction with the care he received throughout his treatment process. He was particularly happy with the attention and professionalism of the doctors involved in his care.
- Male Resident J, a long-term patient at his GP surgery in Stopsley, reported no difficulties in booking appointments and expressed confidence in the treatment provided.
- Female Resident K and Male Resident L, a couple from the community, reported being happy with their GP services. They were able to easily book appointments when needed and did not face significant barriers to accessing care.
- Many residents stated they had a positive experience with the female doctor at Stopsley Village Practice.
- Female resident E identified the good care she had received at the maternity wards at Bedfordshire hospital, with the midwives being very supportive, during her stay in hospital and follow up care in the community.

These positive experiences underscore that, when healthcare services are accessible, the community can benefit greatly from them. They highlight the importance of ensuring that services are consistently reliable and inclusive.

Difficulties Accessing Appointments

A recurring theme across the interviews was the difficulty residents faced in securing timely appointments at local GP practices. Many residents described repeatedly calling the GP surgeries, often without success.

- Female Resident A shared her ongoing struggles to secure an appointment despite having serious health issues, including high blood pressure, sciatica, chest pain, and shortness of breath. She noted that when she called at 8:00 am, all appointments were gone, and she was advised to call back later or the next day—only to face the same outcome.
- Female Resident B highlighted concerns about her children's health, as she found it difficult to get an appointment for them. She mentioned that even when she called early in the morning, appointments were often already booked, and she was asked to call back later, which created anxiety about the lack of timely medical care.
- Female Resident D, who suffers from asthma, faced similar difficulties. She reported calling the GP surgery every day for several days, only to be told that all appointments were fully booked. This lack of access to timely care exacerbated her health concerns.

Some residents expressed concerns that when they stated their address, they were then informed there were no appointments.

The difficulties residents faced with appointment availability created a sense of frustration and helplessness. For many, it led to delays in receiving treatment and medication, further affecting their health and well-being.

Poor Communication and Difficulties Around Appointments

Several residents shared experiences of poor communication and mismanagement of appointments, which caused confusion and added stress.

- Female Resident E, who was pregnant and diagnosed with gestational diabetes, experienced frustration when she attended an appointment expecting to receive a prescription, only to be told that it was not an appointment, but a time to collect the prescription. However, the prescription was not ready, requiring her to return multiple times, and eventually return to the hospital to get the prescription.
- Female Resident A also described her frustration with repeated blood tests, which were lost, requiring her to undergo additional tests. The lack of clear communication around test results and prescriptions created unnecessary delays and complications.

These issues with communication contributed to residents feeling unsupported and neglected by the healthcare system, leading to a lack of trust in the services they relied on.

Lack of Trust in Healthcare Services

A significant number of residents expressed a lack of trust in healthcare providers, particularly due to experiences of misdiagnosis, delayed diagnoses, and poor treatment outcomes.

- Female Resident C shared a particularly distressing experience where she was misdiagnosed with sciatica, when in fact the issue was related to a slipped disc in her spine. Had she received an MRI scan earlier, her condition may have been detected sooner, potentially preventing her from becoming paralysed.
- Female Resident A also shared the experience of a family member who had been misdiagnosed and struggled to get proper care despite repeated efforts. Many residents reported negative experiences of late diagnoses of serious conditions, including cancer, which contributed to their overall lack of trust in the healthcare system.

This mistrust was compounded by concerns about the lack of continuity in care, with some residents describing healthcare providers as dismissive or inattentive to their needs.

Discrimination and Negative Attitudes

Discrimination was another prominent theme in the feedback received. Some residents reported feeling unfairly treated, particularly by reception staff who were described as rude and dismissive when residents identified themselves as part of the Gypsy and Traveller community.

Female Resident G shared her experience of a receptionist refusing to book an appointment when she mentioned her address. She felt that she was treated differently because of her ethnicity, which contributed to a sense of unequal treatment.

Female Resident H described similar issues, with a receptionist being rude and discriminatory, further exacerbating the anxiety and reluctance to engage with healthcare services.

These negative interactions contributed to feelings of marginalisation, making it harder for residents to access services and undermining their confidence in the healthcare system.

Anxiety and Mental Health Concerns

Several residents spoke about the anxiety they experienced around healthcare, particularly in relation to past negative experiences and a fear of misdiagnosis. Female Resident G, who suffers from multiple health conditions, spoke about her fear of visiting the doctor, a fear amplified by the negative experiences of her family members.

- Female Resident H shared her concerns about the high levels of anxiety and depression in the community, particularly in relation to young people, many of whom had lost relatives to cancer or suicide. The lack of mental health support for the community further exacerbated these feelings of anxiety and isolation.

This theme underscores the need for targeted mental health support within the Gypsy and Traveller community, particularly for those dealing with the loss of loved ones or coping with chronic health issues.

Non engagement of health services

Healthwatch Luton (HWL) has identified additional concerns regarding the general health and life expectancy of the Gypsy and Traveller community, particularly stemming from a reluctance to engage with health services. A significant barrier is the lack of awareness about preventive care, such as screening and health promotion, which could improve overall health outcomes.

Many residents reported that their family experiences with health services—often marked by misdiagnoses, delays in treatment, and poor outcomes—contributed to widespread anxiety and a sense of helplessness. This has led to a loss of hope regarding recovery, further compounded by a lack of trust in healthcare providers. As a result, many members of the community choose not to seek professional medical support when they need it.

When asked about sources of support, residents expressed a preference for relying on their families for help, often unaware of the healthcare services or support networks available to them. This limited awareness of external support options exacerbates feelings of isolation and prevents individuals from accessing potentially life-saving services.

Summary of findings

The feedback from the Gypsy and Traveller community in St. Thomas' highlighted both positive and negative experiences with healthcare services.

- **Positive Experiences:**

- Some residents reported satisfactory care, particularly in cancer

treatment and general GP access, underscoring the potential for positive outcomes when services are reliable.

- **Access Issues:**

A recurring issue was difficulty in securing timely appointments. Many residents faced repeated failures in booking appointments, leading to delays in treatment and increased stress.

- **Communication Failures:**

Poor communication and appointment mismanagement were significant concerns. Issues included incorrect scheduling, lost test results, and delays in prescriptions, creating confusion and frustration.

- **Lack of Trust:**

A widespread lack of trust in healthcare providers emerged, driven by misdiagnosis, delayed diagnoses, and inconsistent care, particularly concerning serious conditions like cancer.

- **Discrimination:**

Several residents reported discriminatory treatment from reception staff, exacerbating feelings of marginalisation and making it harder to access services.

- **Mental Health and Anxiety:**

Anxiety around healthcare and fear of misdiagnosis were common, worsened by personal and family experiences with late diagnoses and poor outcomes. Mental health concerns, especially among young people, highlighted the need for targeted support.

In summary, while there are positive healthcare experiences, significant barriers in access, communication, and trust remain, compounded by discrimination and mental health challenges. Addressing these issues is crucial for improving care and outcomes for the Gypsy and Traveller community.

Healthwatch Luton met with members of the Integrated Care Board, Luton Borough Council and Luton Irish Forum to discuss the feedback.

Healthwatch Luton met with Elaine O'Sullivan to discuss the feedback from the residents and discuss ways of overcoming these problems.

The Core20PLUS5 is an approach to reducing health inequalities in Luton, reaching out to the most deprived areas, plus ethnic minority groups including, Gypsy and Traveller communities.

HWL acknowledges the hard work general practice do for the community and NHS, in response to the rising volume and increasing complexity of needs of patients.

Recommendations

HWL met with the care co-ordinator project lead for eQuality Primary Care Network (PCN), who works for Stopsley Village Practice and Ashcroft Practice and discussed the feedback from the residents, as well as ways of improving healthcare for this community:

Difficulties Accessing Appointments

1. **Recommendation:** Improve access to appointment system for English Gypsy and Irish Traveller community offering support with triage system, and easy access to appointments, especially for those with chronic health conditions. **Ensure that 100% of patients are able to get an appointment, with a professional as required, ongoing throughout the next 6 months.**

This will include, to improve contact channels, offering patient choice of access on the telephone, online, and in person, via the new telephone system introduced within GP practices. Barriers may include limited access to the internet, and limited IT and literacy skills.

Reasoning: Many residents reported significant difficulties securing timely appointments, such as Female Resident A, who has ongoing serious health issues including high blood pressure and chest pain but struggles to secure an appointment despite calling early. Female Resident B also expressed concerns about the health of her children but faced similar barriers. The difficulty in booking appointments led to delayed treatment and worsened health concerns.

2. Enhance Communication and Transparency

- **Recommendation:** Establish clearer communication protocols, particularly around appointment bookings, prescriptions, and test results, to reduce confusion and frustration. **Develop and implement a standard communication guideline for all healthcare services in the area, ensuring that 90% of residents report improved clarity regarding their appointments, prescriptions, and test results within the next 4 months.**
- **Reasoning:** Female Resident E experienced significant frustration when she attended an appointment expecting a prescription, only to be told it wasn't an appointment but a time to collect the prescription—only for the prescription not to be ready. Similarly, Female Resident A faced multiple issues with lost blood test results, causing unnecessary delays and additional testing. These issues highlight the need for better communication to avoid confusion and delays.

3. Increase Trust in Healthcare Services

- **Recommendation:** Initiate trust-building campaigns to address the community's concerns about misdiagnoses, delayed diagnoses, and poor treatment outcomes. This could involve healthcare providers engaging more with the community, addressing past mistakes, and ensuring transparent and timely follow-ups. **PCN to organise at least 3 community engagement sessions within the next 6 months where healthcare providers directly address past concerns and commit to continuous improvements in patient care.** This could include, social prescribers from Social prescribers eQuality PCN to focus on proactive engagement by building a relationship with the community. This could involve visiting the community, maintaining a presence for a period of time, where people can come and chat and get health checks, including blood pressure, over the next 3 months. This will include setting up a stall on the site to promote health and/ or door knocking to introduce themselves. Key individuals in the community could be approached to discuss improving health and access to services.
- **Reasoning:** Female Resident C shared her distressing experience of being misdiagnosed with sciatica when the issue was a slipped disc in her spine. This delay in diagnosis almost led to her paralysis. Additionally, Female Resident A mentioned a family member who was also misdiagnosed and

struggled to receive proper care, contributing to a lack of trust in healthcare services. Many residents reported late diagnoses of serious conditions, like cancer, which further eroded their trust.

4. Cultural Competency and Anti-Discrimination Training

- **Recommendation:** Provide cultural competency training for all healthcare staff, particularly receptionists and frontline staff, to address the reported discrimination and negative attitudes towards the Gypsy and Traveller community. **Ensure that 100% of healthcare staff undergo cultural competency training within the next 3 months, this should be followed up with a residents review survey with the aim of improvement in residents' perceptions of respect and dignity when accessing services.**
- **Reasoning:** Discrimination was a recurring issue. Female Resident G shared how she was refused an appointment simply because she mentioned her address, and she felt she was treated differently because of her ethnicity. Similarly, Female Resident H reported a rude and discriminatory interaction with a receptionist, which increased her reluctance to engage with healthcare services. Raise awareness and recognise that there are 2 different communities, the English Gypsy community and Irish Traveller community.

5. Implement Regular Health Promotion and Preventative Care Sessions

- **Recommendation:** Increase awareness of preventative care, such as cancer screenings and vaccinations, by hosting regular health promotion events within the community. These could take place in familiar settings such as community halls, local churches, or mobile clinics. **eQuality PCN to organise at least 1 health promotion event every 3-4 months for the next year, aiming to increase the community's participation in preventative care by 25% within 12 months.** When screening programmes are scheduled at the practice, consider methods of sharing information about education and how to access these screenings (e.g., breast screening).
- **Reasoning:** Many residents reported a lack of awareness and reluctance to engage in preventative healthcare. This is exemplified by the feedback regarding the community's limited knowledge about screenings and vaccinations. Female Resident E, for instance, identified the good care she

received during her pregnancy but noted that such positive experiences were more the exception than the norm. The community needs more proactive engagement in preventive healthcare to reduce the high rates of late diagnoses, such as those seen with bowel cancer.

6. Develop Tailored Mental Health Support Services

- **Recommendation:** Establish accessible and culturally sensitive mental health support services for the Gypsy and Traveller community, particularly for those dealing with chronic health conditions, loss of loved ones, and anxiety about healthcare. **eQuality PCN to liaise with mental health services and set up at least 1 dedicated mental health support group in the next 6 months, targeting anxiety and depression.**
- **Reasoning:** Female Resident H shared her concerns about the high levels of anxiety and depression in the community, particularly among young people, many of whom had lost relatives to cancer or suicide. Anxiety around healthcare was also a prominent theme, with individuals like Female Resident G fearing doctor visits due to negative past experiences. The community's overall lack of mental health support exacerbates these issues, creating a need for tailored, culturally sensitive mental health services.

Next steps

April: Healthwatch Luton will visit the community and feedback the report through leaflets and videos.

May: Healthwatch Luton will visit the community with e Quality PCN's social prescribers, to build relationships with the community and do health checks.

Acknowledgements

Thank you to Luton Irish Forum for introducing HWL representatives to the Gypsy and Traveller community.

Thank you to eQuality PCN for visiting the St Thomas' site and talking to residents and supporting their needs. Also meeting with Healthwatch Luton to discuss the issues and ways of overcoming the problem.

Appendices

Conversation guide: This conversation guide is a set of **q** prompts designed to structure and guide a discussion, aiming to minimise bias and ensure that key topics are covered when asking people about their experiences.

1. First Impressions:

- What was your initial impression of the healthcare system here in Luton?

2. Accessibility:

- Did you find it easy to access healthcare services when you needed them?
- What are your experiences with getting a GP appointment?

3. Understanding the System:

- How easy was it to understand how the healthcare system works?
- What are your experiences when trying to navigate the system?

4. Quality of Care:

- Can you share a specific experiences of using health services?
- What are your experiences with the healthcare professionals you interacted with?

5. Suggestions for Improvement:

- Is there anything you think could be improved in terms of healthcare for travellers here?



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