

St Thomas Gypsy and Traveller Community

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 (H WL) would like to thank Noelette Hanley, CEO of 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:

1. 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.
2. 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.
3. 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'. The data collection occurred during August, September, and October 2024. HWL spoke with twelve residents from the site—eight 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 community.

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 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, and 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 those from this community when accessing local health services were captured, four visits were made to the St Thomas' site to engage with residents and provide them with the opportunity to share their experiences of using both primary and secondary services.

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

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.

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.

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 Mismanagement of 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.

- 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.

1. 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.

2. 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.

3. 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.

4. 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.

5. Discrimination:

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

6. 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.

Recommendations

HWL met with **Elaine**, the manager of Hatters Primary Care Network (PCN), and discussed the feedback from the residents, as well as ways of improving healthcare for this community:

1. Staff training on cultural competency to better meet the needs of the Gypsy and Traveller community.
2. Social prescribers from Hatters 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. This might include setting up a stall on the site to promote health or door knocking to introduce themselves. Key individuals in the community could be approached to discuss improving health and access to services.

3. As trust develops, social prescribers could hold health events and educational sessions in the local church.
4. The new telephone system introduced within GP practices across Luton will reduce waiting times for many patients; however, for the Gypsy and Traveller community, this may not be the case. Barriers include poor internet services, limited access to the internet, and limited IT and literacy skills.
5. Identify other methods of communicating with residents, aside from letters and texts, which residents may not be able to read or may not receive due to poor internet connection.
6. 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).
7. Consider the challenges Gypsy and Traveller communities may experience when accessing healthcare, including issues related to literacy, access to IT, childcare, and transport.

Acknowledgements

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

Thank you to Elaine.....From Hatters PCN for visiting the Stopsley site and talking to residents and supporting their needs.