HWLincs

People's Profile: 'How people live, access, and use health and social care services'

Gypsy, Roma and Traveller (GRT) Communities

HWLincs
3-15-2024

Contents

CONTENT WARNING

This report mentions **sexual assault, substance misuse, domestic abuse, suicide.**

Executive summary

- This CQC People’s Profile project focused on the Gypsy, Roma, Traveller communities.

- We primarily engaged with this group using semi-structured interviews, supported by Easy Read paper and online surveys. The framework covered access to primary care, mental health, cancer and dementia services, and awareness of CQC.

- **The support of the Lincolnshire Traveller Initiative (LTI) and their health champions, the Boswell Traveller family based in Lincolnshire, and GRT mental health support group owner Tanya (case study 1, p. 28), were invaluable to this work.**

- Overall, 55 people shared their views. We heard from a range of ages and respondents identified themselves as follows:
  - Gypsy – 50% (27)
  - Roma – 11% (6)
  - Traveller – 33% (19) – with 6 identifying as Irish Travellers
  - Boater – 4% (2)

Key Findings

The main issues faced by respondents were:

- Access to GP services: no fixed address is a common barrier.

- Negative attitudes and judgement from people in health and care, and a lack of understanding of the community, its needs and culture all influence whether respondents would seek help.

- Hesitance to engage with projects/surveys/feedback is due to a mistrust of authority and institutions due to a) above, b) not feeling as though their opinions are valued, and c) not believing it will make a positive change for their community.
  This hesitance is rising in Lincolnshire and includes even those facilitated by, or in partnership with, organisations that work with figureheads of their community.

- Access to a dentist and a GP were particularly poor.
  - 42% (19) never had access to a dentist.
  - 49% (25) sometimes had access to a GP.
    - The most common barrier appeared to be difficulties registering with a GP mainly due to not having a fixed address but also the attitudes and judgment from some staff.

- Access to online services was mixed. Some respondents outright did not want to use the internet at all to access health services.

  - Barriers to using online services included: it being too complicated, no internet connection, worries about the safety of personal information, and poor computer literacy.

- 48% (25) felt there had been a time they couldn't get the help they needed because of who they are or where they are from.
  - As a result of not being able to register, one respondent shared that they are forced to go to A&E for illnesses such as colds. Another said they "self-medicate". Not being able to get help often meant respondents felt like a burden to others which put them off from seeking help in the future.

- The majority of people, 72% (34), felt they were/had been treated differently when they told a GP or nurse their background. Some disclosed that they never mention their background for this reason. Being treated differently included being spoken to in a patronising way and having their lifestyle and culture misunderstood and stereotyped.

- Worries about being judged, discriminated against, or not understood kindly were the biggest barriers that prevent respondents from feeling comfortable asking for help.

  - Not being able to understand what a GP or nurse tells them had a range of consequences for respondents. These include missing out on information about their care, missing appointments, and taking the wrong amount of medication.

- Good practice relating to treating the community with respect and without judgement was down to individual attitudes and how much they knew about/interacted with the community rather than systems or processes.

- Mental health is a taboo subject within the community.

- Bowel cancer screening attendance amongst male respondents was poor.

- Only 8% (4) of respondents had heard of the CQC. When asked if they would share their thoughts about healthcare with CQC, responses were mixed.

Recommendations

- For co-designing to be truly effective, work first needs to be done to build trust with these communities. They need to be shown that their thoughts and experiences are valued and that their input can lead to positive change.

- Surveys, one-to-one interviews, and group discussions were all ways in which respondents would choose to get involved in co-designing. Respondents generally had a strong preference for face-to-face/in-person activities.

- **Areas to focus on include:**
    - Cultural sensitivity and awareness training for healthcare staff
    - Access to GP services
    - Mental health stigma
    - Bowel cancer screening uptake – especially amongst men.

Organisations worked with

Lincolnshire Traveller Initiative (LTI)

The main organisation we worked with on this project was the Lincolnshire Traveller Initiative (LTI). Our Involvement Officer has a strong relationship with this organisation through past projects. It was agreed that their volunteer Health Champions would facilitate the interviews with residents when they visited the four main sites across Lincolnshire. We created semi-structured interview training and offered it to the volunteers before the interviews.

The LTI was invaluable to this project and we thank them for their support. To show our gratitude a donation (agreed by CQC) was made to the LTI which will be used to fund trips for children in the community.

The Boswell Family

In Spalding, Lincolnshire, is The Gordon Boswell Romany Museum, which was established by and is still run by the Boswell family. The family kindly agreed to share the hard copies of the survey (provided by HWLincs) with family and friends and 10 completed surveys were returned to us.

Tanya – 'Not Ashamed Gypsy Traveler Mental Health' Facebook Group

Content warning – Suicide

Tanya attempted suicide on Christmas Day, 2021. When she left the hospital on Boxing Day, she set up the 'Not Ashamed Gypsy Traveler Mental Health' Facebook group. The private group now has more than 500 members and Tanya hopes it will help people in her community who would previously have felt they have nowhere to turn. Tanya spoke to us about her experiences of mental health services and the work she is doing to tackle the stigma around mental health in the community (case study 1, p. 28).

Key themes

- Society's attitudes towards this group and a lack of understanding of their culture/community is one of the biggest issues they continue to face. Some respondents implied that judgement due to their background was almost inevitable when accessing health and care services. Some respondents shared that they do not disclose their background because of this.

- Many people in the GRT community mistrust "authority"/establishments and don't feel they are part of a society that accepts them. Furthermore, some are now not willing to get involved in projects even if they are supported or facilitated by organisations that they trust and previously had a good relationship with. This is because it was the community feel that too many people 'want to make contact with them and get their feedback but they feel that nothing ever changes', so they fatigue and apply mistrust to figures that are in authority or power.

- People are not able to register with GPs due to having no fixed address and in some cases due to judgment from staff. This can result in them self-medicating, having to attend A&E for relatively minor issues, and health issues escalating to the point that they need emergency care.

- Mental health concerns are isolating. They are not addressed due to stigma within the community and difficulty asking for and getting help outside of it.
  - People struggle to turn to their own community and are discouraged from asking for help from outside.

- Bowel cancer screening attendance amongst respondents was poor, particularly amongst eligible men, who often did not see the need if they felt fine.

- Issues such as domestic abuse are taboo within these close communities. There is a sense this is not safe to discuss.

- Just under half of the respondents shared that they earn less than £18,000 a year.

Recommendations

- When engaging with this group, use a variety of methods including surveys, one-to-one interviews and focus groups. There is a strong preference for engagement to be in-person/face-to-face.

- **However, for any co-designing to truly be effective, considerable work needs to be done to build trust with these communities. From this work, some people shared that they were hesitant to get involved as they feel that many groups approach them but they see no direct benefit to their community as a result. They need to be shown that their thoughts and experiences are valued and that their input can lead to positive change.**

- Cultural sensitivity training/better education for professionals about the community and its needs. E.g. using simple language but not in a patronising way, beliefs about mental health and dementia, and females not wanting to be seen by a male doctor.

- Consider that not everyone wants to or feels comfortable using online services, whether due to no internet connection, or concerns about safety, confidence and literacy.

- Review/refresh access to GPs for those who do not have a fixed address.

- More mobile/one-off/flexible access to GP services for those who are travelling.

- Work with and support the community to help tackle taboos around mental health and to boost bowel cancer screening uptake, especially among men.

- For any work or co-designing to be truly effective with this community there needs to be a focus on gaining the community's trust. Demonstrate that their opinions are valued and that cooperation can lead to positive change.

"Repeat training around the rights and the needs of Gypsy Traveller and Boater communities needs to be compulsory for all healthcare staff."

"Yes, there should be a temporary GP service."

Summary of activities

How did we engage with this group?

Based on our previous experience of working with this community, we knew that an online survey would not be the most effective form of engagement. The main form of engagement used was semi-structured interviews. The questioning framework was broad so we could gain a wider overview of the community's experience of accessing many different health and social care services, with the hope that the findings could trigger some more in-depth research in the future.

The questioning framework covered the following:

- Primary care services (mainly focussing on GP services) – access, staff attitudes and judgment.
- Mental health services – access and effectiveness of support.
- Cancer services – screening attendance and experiences of accessing services such as scans, chemotherapy and radiotherapy.
- Dementia services – attitudes towards dementia and experiences of dementia services.
- Awareness of CQC and how the CQC can involve these groups in the co-designing of services.

Based on our working relationship with these communities, we made sure to use plain, simple language throughout the questions but were sure to avoid being patronising.

The questioning framework was adapted slightly (mainly in terms of formatting) for the online and paper survey. Both the online and paper survey adopted Easy Read images to make it more engaging and user-friendly. We knew that online would not be the preferred method of engagement for many in this group but made sure online participation and survey sharing was widely available through social media and links shared with GRT organisations.

A full copy of the framework for the semi-structured interviews/survey can be seen in the appendix (p. 35).

The engagement activity took place from the 11th December 2023 to 6th February 2024. The majority of the interviews were kindly carried out on our behalf via the Lincolnshire Traveller Initiative's (LTI) Health Champions. This is explained in more detail below.

Method of engagement	Facilitating individual/organisation	Number of people engaged
Semi-structured interview	Lincolnshire Traveller Initiative	40
Online interview	Facebook/HWLincs	1
Paper survey	Boswell Family	10
Online survey	HWLincs	4

Main findings

Who shared their views?

Overall, 55 people from the Gypsy, Roma, Traveller communities shared their views. Respondents identified themselves as:

- Gypsy – 50% (27)
- Roma – 11% (6)
- Traveller – 33% (19) – with 5 identifying as Irish Travellers
- Boater – 4% (2)

We heard from a range of ages, from 18–25, to 56+. Most respondents were women, at 71% (32). For some wider context:

- 23% (11) have a long-term health condition.
- 9% (4) have a disability.
- 11% (5) have experienced domestic abuse.
- 49% (21) earn less than £18,000.

The concerns raised did not appear to be linked to any one part of the wider community. Instead, issues appeared to be more widespread.

A full breakdown of the demographics can be seen in the Appendix (p. 48).

Access to services

When they need medical help, where do they go?

- GP Surgery – 85% (45)
- Accident and Emergency – 51% (27)
- Dedicated organisation (Lincolnshire Traveller Initiative, Friends, Families & Travellers, etc.) – 38% (17)
- Pharmacist – 28% (15)
- Urgent Treatment Centre – 25% (13)

Access to primary care

When asked whether if in the last year, they had been able to access different primary care services when needed, people's experiences were mixed. Access to a GP and a dentist were particularly poor.

In the last year, could you get these services when you needed them?			
🩺	🦷	👓	💊
50% (23) sometimes had access to a GP	**43% (19) never had access to a dentist**	**76% (28) always had access to an optician**	**77% (37) always had access to a pharmacist**

> **"Hard to get an appointment and having to go to A+E to get treated. I can't get into a dentist."**

Case study two (p. 30), which can be read in full in the appendix, raised a notable point about access to medication for those who are travelling. Without the ability to stockpile medication for their travels, they occasionally run out but have had success in getting emergency prescriptions elsewhere, via their home GP. "When we are on the road, sometimes we do not always have enough of our medication as we may only have access to a three-month supply. This has meant on some occasions we have had to call our GP from somewhere else. In most incidences they have been able to get an emergency supply of the medication organised for us somewhere else in the country."

This hasn't always been possible but alternative solutions via the NHS have been found. "On some occasions, we have been advised to become a temporary patient at another surgery to be able to access our medication. We have also used the NHS 111 service. Many people moan about this but we have found them very helpful and again they secured the right information for us at the right time. When we have returned back to Lincolnshire and make contact with our GP they do seem to have been kept up to date with what has happened to us. We feel that we have been very fortunate when we have dealt with clinicians so far."

Overall, 48% (25) felt there had been a time that they couldn't get the help they needed to because of who they are or where they are from. The most common barriers appeared to be difficulties registering with a GP, mainly due to not having a fixed address, but also the attitudes and judgment from some staff.

“I was due for a smear test but had dropped off the list so I went to the local GP and they let me register at the local Post Office, then helped me get an appointment. Being a Boater, I was moving across two counties at the time but had been nomadic on land before that and lost use of a previous care of address.”

“Really hard to register with a GP if you have no proof of address so if travelling you cannot get a GP.”

“Because I move around a lot of doctors won't put me on the register at all.”

“I had chest pains and they didn't want to see me because who I was.”

“When I first moved onto the new site and GP surgery said not taking on new patients and not taking on people from the site. I had to argue with the surgery and eventually got registered at the surgery.”

“Visited GP where I wasn't registered but they wouldn't see me (we were travelling). Practice insisted on an address so wouldn't see me. They said I had to go to my own GP.”

“When you come from a Traveller background they are reluctant to take you on.”

“People are always judging my background.”

“Receptionist was very rude and made me feel like my issues were unimportant.”

As a result of not being able to register with a GP, one respondent shared that they are forced to go to A&E for the likes of colds and another said they “self-medicate”.

“Ended up in hospital as I couldn't get a GP.”

“Can't get into a doctor's surgery because I move about a lot so I always have to go to the A+E department even with things such as a cold.”

Those who were registered with a GP highlighted difficulties getting through on the phone/long waits as a barrier to accessing care.

“Trying to get through on the phone after waiting 30 minutes to get through and getting through to the reception to be cut off.”

Respondents shared that **not being able to get help affected them in many ways** *(listed in order of frequency)*:

"I felt like I was a burden to others."

"I might not want to ask for help in the future because of what happened."

"Things got a lot worse, and I had to go to the emergency for help."

"It made my mental health and overall wellbeing worse."

"It forced me to look for help in other places."

“Not getting the help I needed means that I would not ask for help in the future.”

“Previous experiences mean that I am reluctant to access services.”

Access to online services

- Just over half - 52% (25) - of respondents shared that they can use online services.

- 19% (9) outright did not want to use the internet for health services and an additional 11% (5) did not want to use the internet at all.

- For others, there were a variety of reasons why they could not use online services. These included:
  - “It is too complicated” – 46% (22)
  - “I do not have the internet or my connection is bad” – 23% (11)
  - “I am worried that my personal information will not be safe” – 11% (5)
  - “It is too expensive” – 6% (3)
  - “I am unable to read or write. I can speak English but not read or write” – 4% (2)
  - “I am scared to use the internet” – 2% (1)

- Some felt that not being able to use online services due any of these reasons above served as another barrier to accessing GP services.

“I struggle because I cannot read or write. Staff sometimes say bookings have to be completed online via AskMyGP and don't feel supported.”

“With lack of internet skills, it becomes more difficult.” – ***comment made regarding accessing GP services***

“Getting an appointment can be tricky if you don't have internet connection as it takes longer to get an appointment. The experience sometimes makes you think go straight to A+E.”

“Find AskMyGP is challenging due to literacy issues.”

Communication

Respondents were asked about how staff communicate with them and how comfortable they are asking for help.

When asked if GPs and nurses etc. use words that they can understand, experiences again were mixed. Good practice appeared to be down to individuals rather than systems or processes. Those that had not had a good experience shared that professionals either spoke to them using words they didn't understand, used jargon, or spoke to them in a childlike and patronising way.

> **"No, they do not always use words that I understand."**
>
> **"No - and always talk to me like I am a child."**
>
> **"They need to use more simple language when asking questions."**
>
> **"Definitely not but I think that not everyone understands them. Non-travellers use terms that we as a community do not use and do not understand."**
>
> **"Yes, but for many people the language may be too complex and jargonistic."**
>
> **"Half the time I cannot understand a word that they say."**

Asking for help

Encouragingly, 73% (37) were comfortable asking a doctor or nurse for help. Respondents shared a variety of reasons that make it hard for them to ask a doctor or nurse for help. The biggest barrier appeared to be "worries about being judged, discriminated against, or not understood kindly". Other barriers included feeling "embarrassed", previous experiences, communicating with staff and how staff act.

What makes it hard for you to ask a doctor or nurse for help? *(Tick all that apply)*				
60% (15) **Worries about being judged, discriminated against, or not understood kindly**	**48% (12)** **Embarrassed**	**40% (10)** **Past times you asked for help**	**40% (10)** **Talking or communicating with staff**	**32% (8)** **How healthcare staff act**

Case studies one (p. 28) and two (p. 30) also raised a key point around reluctancy in the community to ask for help. This appeared to stem from historic judgement and discrimination from people outside of their community which as result has forced them to feel that they need to “be strong” and “rely on their own skills”. Case study two urged their community to not let this deter them from seeking help:

“We know that times can be very difficult for people, but we feel that if you work with your GP then things do go much better. We do not demand anything from anyone but sometimes we do need to ask for help. As a proud Traveller family, this has at times been very difficult. However, when you become seriously ill and you have tried our ways, so do need to ask and receive help. This is what has happened to us. Both of us are on medication now that without it we would probably have died years ago or we would have a very poor quality of life.”

Not being able to understand what a GP or nurse tells them had a range of consequences for respondents. This included (listed in order of frequency):

- **"I didn't know what to do."**
- **"I didn't get important information about my health and care."**
- **"I couldn't understand or talk to staff."**
- **"I couldn't get the service I needed."**
- **"My mental health and wellbeing got worse."**
- **"I missed an appointment."**
- **"I might not use GP services in the future."**
- **"I didn't understand how to take my medicine."**
- **"I got the wrong medicine."**
- **"I took the wrong amount of medicine."**
- **"I couldn't decide on my care."**

Attitudes towards Gypsy, Roma and Traveller communities

The majority, 72% (34), felt that they are/had been treated differently when they told a GP or nurse their background. Some disclosed that they never say anything about their background for this reason.

“Yes, I wouldn't tell them. I tell my children not to tell people.”

“I don't tell them my background.”

“I do not tell them as I know that this will make them look at me differently.”

A few respondents went on to explain how they felt they had been treated differently. This included, as mentioned above, being spoken to in an overly simple, patronising way, and their lifestyle and culture being misunderstood and stereotyped.

“Sometimes they think that Travellers don't understand anything and are stupid.”

“Yes, a certain GP tells me instructions time after time like I don't understand.”

“Depending on who I see I definitely feel judged and not taken seriously.”

“Sometimes they seem to think just because we live alternative lifestyles that we don't look after ourselves properly. Some receptionists turn Boaters away and say they can't register us if we don't have a local address.”

“They insult your intelligence.”

“Health visitor seem to pick at everything a lot more than other people.”

“They have no understanding and don't have any training how to treat people from our community / background.”

“Yes and they ask certain types of questions.”

We then asked if respondents had faced problems in a few specific areas due to their background. Respondents answered:

- 52% (24) felt that they have had problems with a GP's receptionist's attitude.
- 43% (20) felt that they have had problems with a GP or nurse's attitude.
- 33% (15) felt that they have received bad care from GPs.
- 29% (15) felt that they have had problems getting a GP appointment.

"In the past staff have tried to get me kicked out of the GP Practice for no reason and are quite ignorant because of my background."

"They need to be more understanding before making a judgement."

"AskMyGP opens before phone line opens so all appointments have gone before you get through on the phone. I never see a GP, it's all done via phone consultation. People go to A+E so they can physically see a nurse or doctor."

When asked if they felt health and care staff treat their community with respect, responses were again mixed. Any good practice appeared to be related to individuals and how much they knew or had interacted with the communities rather than processes or systems.

"It depends on whether surgeries know much about Boaters. It really varies. Some good practice is out there but still some bad too."

"Sometimes yes and sometimes no."

"Some do some don't."

"I once saw a nurse that did that but apart from her, no."

Overall, 56% (27) of respondents generally did not feel that their community was treated with respect by health professionals.

"Definitely not. They do not have the time of day for my kind of people."

"I have been judged but not disrespected."

Mental health and cancer screening in Lincolnshire

Before discussing the findings about mental health and cancer screening it is important to consider some ongoing work in Lincolnshire.

It is important to note that awareness of, attitudes towards, and willingness to seek mental health support and attend cancer screenings among the GRT communities in Lincolnshire may be different to those in other areas. This is because LTI have established two extremely successful Well Woman groups in Gainsborough. These groups have been running for years and cover a wide range of activities intended to improve health outcomes and access to services. Health professionals join the groups to deliver information and practical advice around topics such as mental health, cancer awareness and screening for all of the major health concerns (information taken from the LTI website).

Upon suggestion by Healthwatch Lincolnshire, LTI has worked with the Lincolnshire Partnership NHS Foundation Trust (LPFT) (the Trust responsible for mental health and learning disabilities services in the county), to deliver mental health awareness training for the women in the Well Woman groups. These women then became the first Health Ambassadors for LTI.

This expanded to working with the local community health services (Lincolnshire Community Health Services) to talk to women about screening (breast and cervical screening). The Traveller community through LTI provided a cohort of people that the NHS services link in with and the LPFT / LCHS provides experts to talk directly face to face with the women.

LPFT worked with LTI to co-fund the post of the Link Worker for the community. This post is not a nurse but supports the community in day-to-day concerns that are raised by the community e.g., getting registered with GPs, providing signposting and advice and links into mental health services via the Trust. The first link worker was funded for 12 months as a pilot and due to its success was extended.

Owing to this, ideally, we were hoping to be able to compare the findings relating to mental health and cancer screening in Lincolnshire to other areas of the country, to assess the impact of the above work. However, unfortunately, despite reaching out to multiple other national and regional organisations we were unable to collect sufficient data to make these comparisons.

Mental Health

Mental health is a taboo subject within GRT communities. Eleven respondents shared that they had tried to get help for their mental health but more than half of these individuals did not feel their concerns were taken seriously. Indeed, three individuals went on to share that they were not offered any help and another three felt the treatment they got did not work.

“I was told I could get hit by a bus and that was it. No treatment or support.”

“Was put on medication that didn't agree with me and struggled to get it changed.”

A one-to-one interview exploring mental health amongst the GRT communities:

Content warning: Suicide, prejudice

Following a Christmas Day suicide attempt, 52-year-old Tanya created an online mental health support group for Gypsy Roma Traveller people who feel they don’t have anywhere else to turn. The Facebook group is called the ‘Not Ashamed Gypsy Traveler Mental Health’ and has more than 500 members. Tanya shared invaluable insight into attitudes and awareness towards mental health amongst the GRT communities.

“Because of what we’ve been through, the racism and prejudice against us, we’ve got to be strong. **You’re not allowed to show weakness**,” she said of the GRT approach to mental health. “We're not allowed to show it. And that’s what’s drummed into us.” Tanya said this view held by Elders continues today. “They get embarrassed because it makes them feel as if they're weak. They’ve got no one to turn to, that’s why so many [take their own lives]”.

Tanya has known many people who have died by suicide in her community. “**It's hard for us lot to turn to our own, and it's hard for us to have to turn to somebody else that isn’t our own.** And that’s why I made the group. Because I'm not going to judge. I'm not going to criticise.” She is working hard to break the stigma associated with mental health amongst her community.

The Facebook group is a place designed for safety and security and is run accordingly. “It’s a group for people to express and feel, without any sort of slander. They’re able to speak in confidence.” she said. “That’s why I made the page. Because that split second of suicidal thought, it’s tunnel vision. If in that split second, I’d have been able to talk to somebody. I have people messaging me all the time and I’m there for them. I might never have met them but I’m there. That split second to say, ‘You’re ok, you’re not alone’, is priceless because it can stop somebody from taking their last breath.”

Tanya recognises that nationally, mental health education and conversation has improved but this needs to be platformed to all cultures. She urges GRT people to be more open with their mental health concerns and help others while they have the chance. “Instead of saying, “May they have their best bed in Heaven,’ **say, ‘I'm here for you, you can talk to me. Don't feel ashamed. Don't feel alone. We won't judge’. That’s how things are going to change because we get enough grief without all this on top as well, just for being Gypsy Roma Traveller.”**

Tanya is proud of her Roma-Jewish heritage but feels that GRT groups are unfairly treated by society. “You shouldn’t feel ashamed to be who you are. **A lot of us Gypsies we don't say that we are because of the trouble that comes with it.** There’s good and bad in every culture. The minute you say you’re Roma gypsy traveller, straight away it’s like you’ve got three heads. The NHS isn't too bad. It's more shops, restaurants and general society.”

We greatly appreciate Tanya taking the time to share her story with us. Her insight was invaluable.

The full case study and extended interview is available to read in the Appendix (p. 28).

Cancer Services

Cancer Screening

All respondents eligible for breast cancer screening shared that they had attended screenings. Uptake of cervical cancer screening was also high, especially for those aged 45+. This high uptake of breast and cervical cancer screening might be due to the work of the LTI’s Well Woman groups (as discussed above) and might not be representative of uptake amongst the community in other regions.

However, uptake of bowel cancer screening was low. Indeed, none of the men eligible for bowel cancer screening had been screened. Reasons included the test being too complicated but more commonly not feeling the need to be screened because they felt healthy.

“Have received pack through the post but not yet used it.” – Man aged 56+

“Bowel cancer has too many tests / checks to do.” – Man aged 56+

“Never had a reason to.” – Man

“I am a male and have no problems.” – Man aged 56+

“Never felt that I needed these checks.” – A woman aged 36–45

“Struggle to get appointments.” Person aged 36–45

“No doctor”

“I don't know how to get checked.”

“Don't know if I need all of those screening done.”

Cancer services

Seven respondents shared that they had needed to use cancer services such as chemotherapy or Macmillan and had only praise for the care they have/are receiving.

> **“Worst thing I've ever been through. But every doctor, nurse etc. that I had to see for treatment was very caring and helpful. Couldn't fault anything from treatment to doctors.”**
>
> **“Not the best time of my life. The care from the consultants down to the cleaning lady was first class.”**
>
> **“Brilliant service no complaints at all. Still on chemotherapy tablets. Quick service and seen promptly.”**
>
> **“Was all good and after care has been good.”**

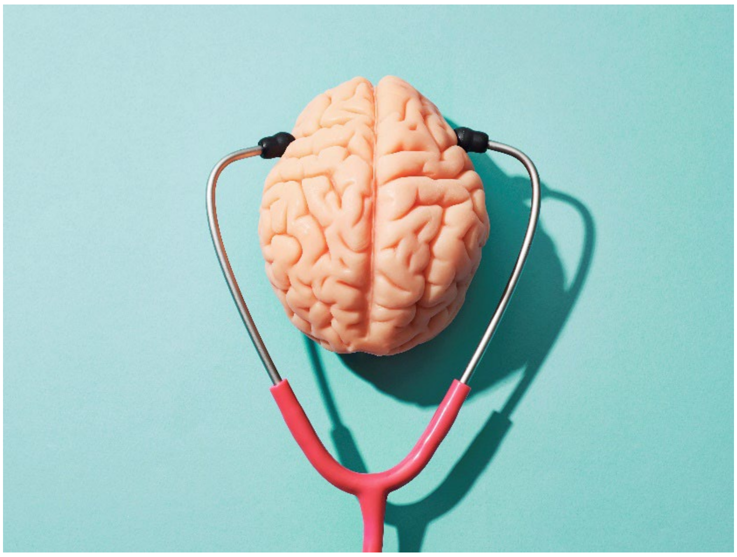
Dementia

Attitudes towards dementia

Attitudes towards dementia were mixed. Overall:

- 35% (15) believe that “people with dementia cannot make decisions for themselves”.
- 82% (35) believe that “people with dementia must have enjoyable activities to do”.
- 45% (19) neither agreed nor disagreed that “people with dementia forget everything you say”.
- 56% (24) agreed that “people with dementia can do lots of things”.

76% (35) said they would see their GP if they were worried about dementia.



Dementia services

Five individuals shared they had accessed dementia services, one for themselves and four to help support someone else. One individual had a positive experience at the memory clinic. However, others did not. This was due to long waits but mainly a lack of understanding of the needs and culture of the community.

“It was okay in the end. My grandad had dementia and took ages to get help such as carers and respite. Eventually he had to go into a care home where we had to have a meeting with staff to make them aware of his background (Traveller) because he didn't want to be inside even in winter so our family brought the care home house a gazebo which helped with the situation.”

“It was okay but nurses and doctors don't always understand that my community have lots of visitors. Travelling people are all about family and visiting to show respect to the family members and friends.”

“It was quite frustrating to get help and took a long time but eventually did.”

“They don't really put the patient first.”

CQC awareness, involvement in decision making and co-designing

Only 8% (4) of respondents had heard of the CQC. When asked if they would share their thoughts about healthcare with CQC, responses were mixed. 33% (13) said they would. However, 41% (16) were “not sure” and 26% (10) said outright they would not share they views.

Just 23% (10) felt that health and care staff understood the community's needs and how they want these needs to be met. Even fewer - just 11% (5) - felt that their community is thought about when decisions about health services are being made.

“Sometimes most don't want to engage, others don't seem to be bothered.”

“Depending on who I see I definitely feel judged and not taken seriously. No they don't understand all situations that they as non Travellers they do not understand e.g., being checked in certain parts of the body as a woman by a male.”

“They don't always understand. I think they should learn about my community like any other ethnic group.”

“They do not understand our people and our culture.”

“There needs to be better understanding about the Boater community and that we have to move around if we don't have a home mooring so that often we might need healthcare or medicines but we might be many miles away from our registered surgery. Even though some Boaters do have moorings they may still have to use a care of address as no actual address exists for the mooring. So the address may be in a different county and boaters may miss post from surgeries.”

When asked how they would like to get involved, it was clear that there was single preferred method. Surveys, one-to-one interviews, and group discussions were all ways that respondents would choose to get involved. Respondents generally preferred face-to-face/ in-person activities to online/virtual engagement.

Surveys, one-to-one interviews, and group discussions were all ways respondents would choose to get involved.

Recommendations for CQC on co-designing with these communities

The majority of respondents did not feel that the needs of their community are well understood. Nor did they feel that their community is thought about when decisions about health services are being made. However, there is a hesitancy amongst some people to get involved and change this. This mainly stemmed from the discrimination and judgment that this group continues to face, compounded with a lack of understanding of their culture. As a result, many mistrust “authority”/establishments and feel that they are outside of a society that they feel doesn’t accept them. Furthermore, many are now not willing to get involved in projects even if they are supported/facilitated through organisations that they trust and previously had a good relationship with. This is because the community feels that too many people “want to make contact with them and get their feedback but they feel that nothing ever changes” so they mistrust figures that are in authority or power.

For co-designing to be truly effective, work first needs to be done to build trust with these communities. They need to be shown that their thoughts and experiences are valued and that their feedback or input leads to positive change.

For those who would be willing to get involved in co-designing, there was a strong preference for in-person/face-to-face methods. Surveys, one-to-one interviews and focus groups were all ways that respondents would be willing to get involved. The findings from this work highlighted several potential areas where co-designing would be beneficial, including cultural sensitivity training for professionals, access to GPs and cancer screening, especially bowel cancer screening among men.

Evaluation

Other individuals/organisations we reached out to

We reached out to the Boston Borough Council Wellbeing Network who shared the survey via the Community Leadership Bulletin. They also directed us to the Community Leadership Officer at the council who has a contact who facilitates engagement with the Boston community on the Redstone Site. Unfortunately we were unable to engage with this community. The contact shared: *“They have been thinking about potential implications for her appearing to support anything that may be used against them. The travellers are very suspicious of any services and they fear negative repercussions if they associate with anything official.”*

We also reached out to the practice manager and PCN lead for the GP surgeries that cover the Boston Community. We asked if the survey could be shared via patient participation groups (PPGs) and online through the practice website, however, we received no response. Similarly, we also reached out to the patient experience manager for our ambulance services (East Midlands Ambulance Service (EMAS)) asking if they could share the survey both hard copies and the online link at their patient voice group meetings and via their social media platforms. Again, no response was received. We also reached out to the community connectors in Lincolnshire but again received no response. We followed up communication with all these individuals but to no avail.

To broaden our reach to the GTR communities outside of Lincolnshire we reached out to national (N) and other regional (R) organisations including:

- Friends, Family and Travellers (N)*
- Race Equality Foundation (N)*
- The Traveller Movement (N)
- Roma Support Group (N)
- One Voice 4 Travellers (N)
- Gate Herts (R)
- York Travellers (R)
- Travellerspace Cornwall (R)
- Equity (N)
- London Gypsies and Travellers (R)
- Leeds Gate (R)
- The Allen Lane Foundation (N)

*Despite reaching out to these organisations’ multiple times via email and phone, keeping them up to date with the progress of the project and again asking for their support, no response was ever received.

Furthermore, previously our Involvement Officer was involved in a Healthwatch England project working with the GRT communities alongside four other Healthwatchs. We also contacted these different Healthwatchs to ask if they would share the survey in their communities. Unfortunately, no responses were received.

The following Facebook groups were asked to share the survey link to their members:

- Appleby Horse Fair
- Gypsy-Travellers Essex
- Romany ("Gypsy") and Pavee ("Irish Travellers")' Rights and Awareness

- I'm a Romany Gypsy and proud of it!!!
- Gypsy traveller Romany London
- GYPSY TRAVELLERS IN DORSET
- Not Ashamed Gypsy Traveler Mental Health
- Gypsy and Travellers World
- Lets STOP Racist Hatred Against Gypsy and Travellers PLEASE REPORT !
- Appleby Horse Fair, the biggest and best in Europe
- The Original Appleby Horse Fair

Final reflections

- One of the biggest takeaways from this project was the apathy among the community and reluctance to engage in this type of work. It was expressed through LTI, that a growing number of health and care organisations are approaching the Traveller Community and the community was finding this unsettling on the whole and are seeing little benefit as a result. For future projects to be successful, apathy and mistrust needs to be addressed by ensuring there will be some positive, tangible outcomes for the participating communities.

- Many of the topics discussed through this work refer to themes in health and care that are not openly discussed and can be seen to be more probing than the community feels is necessary. Also, other topics such as domestic abuse are often not discussed due to the close nature of the community. Members likely do not feel comfortable disclosing this information as people would be able to work out who they were talking about.

- One concern/reflection raised by the LTI was the timing of the engagement. During the lead up to the festive season of Christmas many people from this community make long travel plans to spend time with family and friends across the country making engaging with them more challenging. This may in part also have contributed to the low engagement from other organisations.

  Indeed, the main identified organisation that works directly with this community, Lincolnshire Traveller Initiative (LTI), work school term time only with limited staff during school holidays.

- The community prefers face-to-face, semi-structured interviews, so it was helpful to know that the Health Ambassadors from the community would support to carry out the interviews on our behalf. However, due to challenges within the community and in spite of being offered support from HWLincs/Healthwatch Lincolnshire staff, they did not take up the offer of additional support in training and assistance.

- The length of the questioning framework and the number of different areas that the CQC wanted information on initially caused some challenges as the representatives from the community felt that the framework was too long. To mitigate this, the online survey digitally streamlined the questioning through automation and both surveys reduced wordiness and used Easy Read icons.
- An online version was shared but many of the community find this way harder to access due to either lack of access to technology or lack of skills including literacy and IT skills. This was a good way to get the survey out to groups in the community via social media.
- We ensured enough hard copies of the questioning framework were produced and given to the community in a timely manner to start before the end of the term. We would have no control over the quality of the interviews that took place to capture all of the person's feedback. As experienced engagement personnel, we can adapt our language to ask probing questions and record this information. E.g., "it's a good service….." we would explore this a bit further by asking for examples of what they meant.
- The lack of support from national organisations was disappointing.
- Working with the community through partners has its pros and cons. On the one hand, the community trust the partner organisation and may feel happier to engage with them, especially in areas within the county that we have not worked with the community directly. However, our contacts were given the opportunity for a dedicated member of our team to work alongside them to encourage people to be part of the project but this was not taken up.
- It was challenging to get the community to engage in the work. There was a sense of mistrust from the community in engaging with representatives from an outside organisation and the perceived consequences that it raised.
- Once the report has been submitted, findings analysed and discussed it is very important that findings and what happens next is shared with the community. The "you said, we did" ethos is important, so that the community feels that they were truly listened to and that changes are being made to improve access to health and care services. This information should be shared with the community in a suitable format such as a video, Easy Read and infographics.

Appendix

Case Studies

The case studies in this report were conducted on the understanding that in exchange for an honest and open discussion of the issues faced, the people who shared their stories would be provided anonymity. As such, names and identifying details have been omitted, except for Case Study 1, for which the interviewee consented to being named.

Case Study 1

Interview

CQC People’s Profile: Gypsy Roma Traveller
Date: 7/2/24
Method: Social media messenger / voice messages

Content warning: Suicide, prejudice

Overview

Following a suicide attempt, 52-year-old Tanya created a mental health support group for Gypsy Roma Traveller (GRT) people who feel they don’t have anywhere else to turn. Tanya said that historical and current treatment of GRT people by society has forced them to adopt a strong, silent approach to mental health problems. This leaves people feeling isolated, alone and suicidal in a community that does not openly address mental health issues.

Case Study

Tanya attempted suicide on Christmas Day, 2021. When she left hospital on Boxing Day, she set up the ‘Not Ashamed Gypsy Traveler Mental Health’ Facebook group. The private group now has more than 500 members and Tanya hopes that it will help people in her community who would previously have felt that they have nowhere to turn. “Because of what we’ve been through, the racism and prejudice against us, we’ve got to be strong. You’re not allowed to show weakness,” she said of the GRT approach to mental health. “We're not allowed to show it. And that’s what’s drummed into us.” Tanya said that this view held by Elders continues today. “They get embarrassed because it makes them feel as if they're weak. They’ve got no one to turn to, that’s why so many [take their own lives]”.

Tanya has known many people who have died by suicide in her community. “It's hard for us lot to turn to our own, and it's hard for us to have to turn to somebody else that isn’t our own. And that’s why I made the group. Because I'm not going to judge. I'm not going to criticise.”

If the group helps just one person, Tanya considers her job done. But in reality it’s likely to be helping many more. “I'm going to talk to another Gypsy in confidence without them being made to feel weak and not judged. That's why I made the group. I want to help other people feel that they have somebody. I thought I had nobody that Christmas Day," she said.

Tanya is proud of her Roma-Jewish heritage but feels that GRT groups are unfairly treated by society. "You shouldn't feel ashamed to be who you are. A lot of us Gypsies don't say that we are because of the trouble that comes with it. There's good and bad in every culture. The minute you say you're Roma gypsy traveller, straight away it's like you've got three heads. The NHS isn't too bad. It's more shops, restaurants and general society."

For six months following her suicide attempt, Tanya was in daily contact with the NHS Crisis team. She also received financial support from The Roma Gypsy Traveller Organisation. Tanya is now in contact with her GP for medication but otherwise describes herself as a recluse. "I don't want to go out my house. I don't see door to anybody. I could be here dead and nobody would know. But I'm a strong girl. I'm a strong woman. And that's what life has taught me."

Tanya's arms are covered in tattoos that celebrate her heritage and getting more is all that she leaves the house for ("it's like therapy for me," she said). "I've had my tattoos done in honour and memory of my mother and my Romany ancestors because a lot of the things with the history and the culture, it's all dying out. Because government's trying to eradicate everything about us," Tanya added.

After losing family members to suicide and feeling the pain of facing suicidal thoughts alone, Tanya takes a strong stance against traditional GRT views that follow the death of someone to suicide. "I am trying to change things," she said. "When people pass away, people say, 'May they have their best bed in Heaven'. I think, 'Well where were you? Why could they not turn to you? If they thought they could turn to you, maybe they'd still be here.' That's what I'm trying to do. I'm trying to open it up where, no it's not shameful to have poor mental health," she said.

"You feel. We're allowed to feel. We're human. We can have feelings. We can be emotional. We can be unstable, we can be vulnerable. We're human beings. We don't have to be this hard, tough exterior all the time. But it's all we know because we've been made like this because of society. We've had to be, and old habits die hard."

The Facebook group is a place designed for safety and security and is run accordingly. "I won't take any bullshit. If people come on there judging, like they have done, I've booted them off the group. It's a group for people to express and feel, without any sort of slander. They're able to speak in confidence. It's not going to get repeated. To be able to open up and feel like they're with somebody who'll support them," she said.

"That's why I made the page. Because that split second of suicidal thought, it's tunnel vision. If in that split second, I'd have been able to talk to somebody… I have people messaging me all the time and I'm there for them. I might never have met them but I'm there. That split second to say, 'You're ok, you're not alone', is priceless because it can stop somebody from taking their last breath."

Tanya recognises that nationally, mental health education and conversation has improved but this needs to be platformed to all cultures. She urges GRT people to be more open with their mental health concerns and to help others while they have the chance. "Instead of saying, "May they have their best bed in Heaven,' say, 'I'm here for you, you can talk to me. Don't feel ashamed. Don't feel alone. We won't judge'. That's how things are going to change because we get enough grief without all this on top as well, just for being Gypsy Roma Traveller."

Outcomes and Observations

Tanya has dedicated herself to supporting others and within that, found support for herself within a closed corner of the GRT community for people in need. She uses this opportunity to try to encourage others within the community to be open and honest with each other. It is clear that more work is needed to extend the national mental health dialogue to cultures such as GRT communities. The dual stigma of both a GRT background in wider society and the stigma of mental health within the GRT community is a double barrier that clearly stops many from getting essential help and resulting in suicide.

Case Study 2

Interview

CQC People's Profile: Gypsy Roma Traveller
Date: 15/2/24
Method: Interview

Overview

This case study is the story of B, a showman in his mid-70s. A showman is defined as a person who travels with fairs around the country during the summer months. The traditional season runs from Easter until November. He and his wife have long-term health conditions that they manage with medication, prescribed by the GP local to their settled community. With limited supplies on the road, they have been able to call their GP to organise medication collection elsewhere. The barrier of asking outsiders for help is addressed and B urges people to do so, despite cultural expectations.

Case Study

B is a Gypsy Traveller showman in his mid-70s. His showman role means he travels nationwide with fairs for four to five months of the year. When not on the road, he lives with his wife on the east coast of Lincolnshire in a settled community. "We live in a house as we want some of the comforts in life as we get older. My wife and I both have long term conditions (COPD and diabetes). We are registered at our local GP practice and we can honestly say that we have never experienced any disrespect from anyone at the doctor's surgery.

"We believe in giving respect to people who dedicate their lives to medicine and support people like myself who live a different live to most people."

Due to aging, B's life has changed since he started his work. Minor health concerns were handled personally but as issues became more complex, he and his wife have had medical support. "When we were younger we were on the road a lot and very healthy. But on some occasions we may become ill as many people do and we learned how to look after ourselves and relying on our own skills. However, when we received news that things were not going so well we approached the surgery when we got back to Lincolnshire and we were treated very well and got a really good service."

B urges people in his community to engage with their local GP, even if it means asking for help. "We know that times can be very difficult for people, but we feel that if you work with your GP then things do go much better. We do not demand anything from anyone but sometimes we do need to ask for help. As a proud Traveller family, this has at times been very difficult," he said. "However, when you become seriously ill and you have tried our ways, so do need to ask and receive help. This is what has happened to us. Both of us are on medication now. Without it we would probably have died years ago or we would have a very poor quality of life."

Without the ability to stockpile medication for their travels, B and his wife occasionally run out but have had success in getting emergency prescriptions elsewhere, via their home GP. "When we are on the road, sometimes we do not always have enough of our medication as we may only have access to a three-month supply. This has meant on some occasions we have had to call our GP from somewhere else. In most incidences they have been able to get an emergency supply of the medication organised for us somewhere else in the country," B said.

This hasn't always been possible but alternative solutions via the NHS have been found. "On some occasions, we have been advised to become a temporary patient at another surgery to be able to access and have been able to access our medication. We have also used the NHS 111 service. Many people moan about this but we have found them very helpful and again secured the right information for us at the right time. When we have returned back to Lincolnshire and make contact with our GP they do seem to have been kept up to date with what has happened to us. We feel that we have been very fortunate when we have dealt with clinicians so far."

As well as the long term conditions, B also had a health scare that resulted in time in hospital with suspected pneumonia. "It ended up being a very nasty chest infection that I could not get rid of and my wife nagged me into getting checked out. I needed a strong dose of antibiotics and a few days in hospital and then followed by a few days at home. The local hospital respected our ways and allowed family and friends who had travelled long distances to sometime come and visit outside of the normal visiting hours. This was greatly appreciated and helped me to recover. We as a family, have had very good service from the NHS. Thank goodness it is here."

Outcomes and Observations

This person has accepted that as he's got older, he has had to break from the expectation of not asking people from outside of his community for help and by his account, has only had positive experiences as a result. These include from his GP, other GPs, NHS 111 and a hospital. He urges other to ask for help when needed.

Case Study 3

Date: 26/2/24
Method: Interview

Overview

The person identifies as a New Age Traveller and a Boater. Due to having no fixed address and travelling waterways, they cannot register with a GP on the move and feel their health and wellbeing has suffered due to this.

Case Study

P is a New Age traveller and a Boater. She is a woman, aged 26-35 and has a long-term health condition. Boaters are defined by the UK Government as Travellers but as a lifestyle. "Boaters are not an ethnic minority; it is seen as a lifestyle choice although many Boater families have lived on the water for generations." She has not seen a GP in the last year because she is on the move, so is deemed as having no fixed address. "Many surgeries don't accept NFA and insist you have proof of address," she said. "I get my post sent to a relative in a different city so I can only register in that different city. This makes traveling to the doctor very difficult, time-consuming, impractical and expensive so I don't bother."

This barrier to healthcare has resulted in a number of negative issues arising and their go-to health services being A&E and UTCs, only when problems have deteriorated and reached emergency levels.

The lack of GP access caused her to suffer, affecting her mental health, her physical wellbeing, she felt like a burden to others and said that she might not ask for help in the future because of her experience.

She suggests that for people with no fixed address, access to general healthcare should be available on a walk-in basis. "I have heard of one that does in London but I'm often nowhere near it. I feel Boaters should be able to attend walk-in clinics more easily," she said.

Being over 25, she is eligible for routine cervical cancer screening. These are usually offered via a person's GP but without being registered at one, she has not had any information on this and has not attended a screening. “I'm not sure what screenings I'm meant to go to,” she said.

She added that if she had concerns about dementia symptoms, she would not see a GP. “Seeing a GP is hard as a traveller, particularly hard after all these cuts to social services,” she said.

As well as problems getting GP appointments, she has also experienced issues with the attitudes of staff and “bad care”. She said she is not comfortable asking doctors or nurses for help due to how they act towards her, past experiences, how they communicate with her, worries about being discriminated against and feeling embarrassed.

P reads, writes and understands English well but digital literacy is a barrier to accessing online services, as well as connectivity problems.

She had not heard of CQC but would be willing to share her healthcare experiences via postal surveys.

Outcomes and Observations

Travellers with no fixed address face issues accessing GP services, which causes emergency treatment centres (A&E/UTCs) to be their only port of call when their condition is sufficiently bad to warrant urgent care. Compounding this, experiences of prejudice cause people to choose to not engage as they fear that they will face similar issues, resulting in worsening health.

Case Study 4

Date: 2/2/24
Method: Survey Feedback

Overview

This is the story of a woman aged 46-55 who identifies as a Boater. Due to this way of life, she has had to be proactive to get the healthcare she needs and feels she has faced discrimination by staff when trying to get appointments. She believes that healthcare staff need to be educated on the needs of Boaters.

Case Study

D, a woman aged 46-55 and a Boater, was due a smear test but having “dropped off” the list, she registered with a GP at the county she was in at the time. This took work and she is concerned that other people who might not have the tenacity or understanding will miss out on essential healthcare. “I went to the local GP and they let me register at the local Post Office, then helped me get an appointment. Being a Boater, I was moving across two counties at the time but had been nomadic on land before that and lost use of a previous ‘care of’ address,” she said. “I had to be proactive and ask them to get me back on the register and produce an appointment for me. Others might not have kept demanding it and let it slip.”

She said she has been turned away by some GPs. “Some receptionists turn Boaters away and say they can't register us if we don't have a local address. Sometimes they seem to think just because we live alternative lifestyles that we don't look after ourselves properly,” she said.

D thinks that access to healthcare should be made easier to Boaters, and that an understanding of their lifestyle would help make this change. “There needs to be better understanding about the boater community,” she said. “That we have to move around if we don't have a home mooring so that often we might need healthcare or medicines but we might be many miles away from our registered surgery. Even though some Boaters do have moorings they may still have to use a ‘care of’ address as no actual address exists for the mooring. So the address may be in a different county and boaters may miss post from surgeries.”

Her negative experiences vary based on staff’s knowledge, she said. “It depends on whether surgeries know much about Boaters. It really varies. Some good practice is out there but still some bad too.”

D recommends that healthcare staff should undergo specific training in order to improve the service given and the healthcare outcomes of Boaters and Travellers. “[They need] repeat training around the rights and the needs of Gypsy Traveller and Boater communities. It needs to be compulsory for all healthcare staff,” she said.

D said that accessing online GP services is too complicated. She speaks, understands and reads English well but feels that language used by doctors, nurses etc “may be too complex and jargonistic for many people”.

Outcomes and Observations

Experiences and access to healthcare vary based on frontline staff’s knowledge and acceptance of traveller lifestyles, according to the interviewee. Training could be put in place for people to understand their needs and how they would differ from settled people, and a pathway for access to care could be in place to make sure that people away from their ‘care of’ addresses get timely access to healthcare.

Survey and Interview Questions

For this group the survey and interview questions were the same. Some groups were given the questions to complete by themselves (as a survey). For the other groups, with the support of the LTI and their volunteers the survey was used as an interview framework, whereby the volunteers spoke to respondents about their experience.

Gypsy, Roma and Traveller Questioning Framework

1. Are you:

☐ Gypsy
☐ Roma
☐ Irish / Welsh / Scottish Traveller (circle yours)
☐ Other, please share below:

2. When you're not feeling well, where do you go for help? (choose all places you go)

☐ GP
☐ Accident and Emergency (A&E)
☐ Pharmacist
☐ Urgent Treatment Centre (UTC)
☐ Other, please tell us more:
☐ Charity (e.g. YMCA)
☐ Dedicated organisation (Friends, Families & Travellers etc)

3. Has there ever been a time when you felt you couldn't get the medical help you needed because of who you are or where you come from?

👍	👎	?	⊖
Yes	No	Not sure	I don't want to say
	(go to Q5)		

If that's happened to you, what happened and how did it affect you. What did you do next?

4. **How did not being able to get help affect you? (Tick all that apply)**

☐ It made my mental health and overall well-being worse
☐ Things got a lot worse, and I had to go to the emergency for help
☐ I might not want to ask for help in the future because of what happened
☐ I felt like I was a burden to others
☐ It forced me to look for help in other places
___***Where did you go?***

☐ Other, please tell us more

About the times when you need to see a GP

5. When you tell a GP or nurse your background, do you think they treat you differently?

6. **In your experience, do health and care staff:**

a) Understand what your community needs and how you want to get it?

b) Treat you with respect?

7. In the last year, could you get these services when you needed them?

	Yes, always	Sometimes	Never	Not needed
GP				
Dentist				
Opticians				
Pharmacist				

8. Did you have any problems because of your background:

	Yes	No	Not sure	N/A
Getting a GP appointment				
GP's receptionist's attitude				
GP or nurse attitude				
Bad care from GPs				

9. Is there anything else you want to share about your experience in trying to get a GP appointment?

(Prompts for interview/focus group:)

- *Getting an appointment e.g. difficulties registering with practice, getting through on the phone or online/ availability of appointments*
- *Attitudes of staff to them trying to get appointment/judgement/inappropriate comments*
- *Has their experience put them off from trying to access care in the future*

10. Can you use online services?

☐ **I can** use online services
or
I can not use online services because…(tick all that apply)
☐ It is too complicated
☐ It is too expensive
☐ I do not have the internet or my connection is bad
☐ I am worried about my personal information will not be safe
☐ I am scared to use the internet
☐ I don't want to use the internet
☐ I do not want to use the internet for health services
☐ Something else:

11. Speaking and writing English (please choose one):

😀	🙂	☹	?	⊖
I can speak, understand and read English **well**	I can speak, understand and read English **a bit**	**I can't** speak, understand or read English	I don't know	I don't want to say

12. Do GPs, nurses, etc) always use words that you understand?

This could be about the words they use or how they talk to you, like on the phone or in letters.

13. Are you comfortable asking a doctor or nurse for help?

👍	👎	⚠
Yes	No	I did not know I that can ask for help
(go to Q16)		

14. What makes it hard for you to ask a doctor or nurse for help? (Tick all that apply)

☐ How healthcare staff act
☐ Past times you asked for help
☐ Talking or communicating with staff
☐ Worries about being judged, discriminated against, or not understood kindly
☐ Embarrassed

15. When I don't understand what a GP or nurse tells me: (Tick all that apply)

☐ I might not use GP services in the future
☐ My mental health and well-being got worse
☐ I didn't get important information about my health and care
☐ I couldn't get the service I needed
☐ I couldn't understand or talk to staff
☐ I couldn't decide on my care
☐ I missed an appointment
☐ I didn't know what to do
☐ I got the wrong medicine
☐ I took the wrong amount of medicine
☐ I didn't understand how to take my medicine

Access to mental health support

16. Have you ever tried to get help for your mental health?

👍	👎	⊖
Yes	No	I don't want to say
	(go to Q19)	

17. Did your GP take your concerns about mental health seriously?

👍	👎	❓	⊖
Yes	No	Not sure	I don’t want to say

Any further comments:

18. Did the treatment you got..?

😃	☹	❌	⊖
Work well	Not really work	I was not offered any help	I don’t want to say

Any further comments

Cancer Services

19. Have you gone for these health checks?

	👍 Yes	👎 No	? Not sure if I'm supposed to go for it	⊖ I am not supposed to go for it
Breast Cancer (mammogram)				
Cervical Cancer				
Bowel Cancer (poo check)				

20. If not, is there a particular reason why?

21. Have you had to use cancer services like chemotherapy, radiotherapy, Macmillan or scans?

👍	👎	⊖
Yes	No	I don't want to say
	(go to Q23)	

22. If yes, how was it?

Dementia Services

23. Do you agree or disagree with these statements?

	Agree	**Neither agree nor disagree**	**Disagree**	**I don't want to say**
People with dementia can not make decisions for themselves				
People with dementia must have enjoyable activities to do				
People with dementia forget everything you say				
People with dementia can do lots of things				

24. If you were worried about dementia or your memory, would you see a GP?

Yes	No	Not sure	I don't want to say

If not, is there a reason why?

26. Have you used Dementia Services?

👤	👥	👎	⛔
Yes, for myself	Yes, supporting someone else	No	I don’t want to say

27. What was it like?

The CQC

28. Have you heard of CQC (Care Quality Commission)?

👍	👎	?	⊖
Yes	No	Not sure	I don’t want to say

29. The CQC collects good and bad stories about healthcare.
Would you choose to share your experiences with CQC?

👍	👎	?	⊖
Yes	No	Not sure	I don’t want to say

30. Do you feel that your community is thought about when people make health services?

👍	👎	?	⊖
Yes	No	Not sure	I don’t want to say

31. How would you choose to help these people know what you need?

In person surveys	Online surveys	Surveys through the post	Talking in a group
		?	✕
Online meetings	Interviews, talking to one person face to face	Not sure	I would not like to help

Something else (please let us know)

About You

This helps us understand how your treatment compares to others. Like everything else in the survey, your answers are private, and no one will know it's you.

If you do not want to answer these questions, please skip to question **4** and tell us why.

1. How old are you?

☐ 18 – 25
☐ 26 – 35
☐ 36 – 45
☐ 46 – 55
☐ 56+
☐ I don't want to say

2. Are you:

☐ A woman
☐ A man
☐ I don't want to say

3. Please tick a box for each question

	Yes	No	Not sure	I don't want to say
English is the language I know best				
I am homeless or have been homeless				
I have a disability				
I have a long-term health condition				
I am a refugee or asylum seeker				
I have experienced domestic abuse				
I have been in the criminal justice system				
I have experienced modern-day slavery and/or sex-trafficking				
I was taken into care as a child				
I am a carer				
I receive or earn less than £18,000 a year				

4. I do not want to fill this part in, because:

☐ I do not see why you need all this information
☐ I do not want you to have all this information about me
☐ There is no point filling it in
☐ Something else (please tell us):

Demographics

Demographic	**Percentage (number)***
Gypsy	50% (27)
Roma	11% (6)
Traveller	33% (19)
Irish Traveller	6
Boater	4% (2)
Did not answer	4% (2)
Age	
18 – 25	27% (12)
26 – 35	11% (5)
36 – 45	25% (11)
46 – 55	20% (9)
56+	16% (7)
Prefer not to say	2% (1)
Did not answer	9
Gender	
Woman	71% (32)
Man	20% (9)
Prefer not to say	9% (4)
Did not answer	9
Speaking and writing English	
I can, speak, understand and read English well	76% (39)
I can speak, understand and read English a bit	22% (11)
I don't know	2% (1)
Did not answer	3
English is the language I know best	100% (47)
I have a long term health condition	23% (11)
I have a disability	9% (4)
I am homeless or have been homeless	7% (3) (inc 1 Not sure)
I am a refugee/asylum seeker	0% (0)
I have experienced domestic abuse	11% (5)
I have experienced the criminal justice system	0% (0)
I have experienced modern-day slavery and/or sex-trafficking	0% (0)
I was taken into care as a child	0% (0)
I am a carer	9% (4)
Roughly, in total I receive or earn less than £18,000 a year	49% (21)
I use substances in a way that may be considered misuse or outside of recommended use	0% (0)
County/Location	
Lincolnshire	96% (44)
Oxfordshire	2% (1)
England	2% (1)

***Totals may exceed 100% due to rounding**

Care Quality Commission

HW Lincs The Engagement to Insight People

healthwatch Lincolnshire

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