Continuous engagement with people who are from Black and minority ethnic communities to explore any barriers they may face when accessing care

May 2022

About Us

Healthwatch Surrey CIC is an independent health and care champion, empowering the residents of Surrey to have their voices heard. We seek out people's experiences of health and care services and share these with service providers and decision-makers, to support services to improve and tackle health inequalities. We believe that health and social care providers can best improve services by listening to people's experiences.

We also provide advice and signposting to help the people of Surrey find the care that best suits their needs. All appropriate information and advice and signposting to complaints processes has already been given. Any urgent or concerning experiences within this report have been escalated to the appropriate support services.

All names have been changed to protect anonymity.

Engagement Summary

We spoke with 44 Surrey residents for whom English is a second language, 11 of whom were refugees / Asylum seekers.

In March and April, we engaged with 6 community organisations who were providing a range of support services for individuals from minority ethnic backgrounds, primarily offering English language and computer classes, as well as social and lifestyle activities.

The groups we attended were comprised of around 10-12 individuals, many of whom were regular attendees. As the group activities carried on as usual, we invited respondents to speak with us in small groups of 2 or 3, where we were able to have semi-structured conversations prompted by a series of questions around their experiences in accessing care. In one case, a group was comprised of 4 attendees so we conducted the conversation as a focus group.

The younger respondents were supported by a housing association and in this circumstance, we set up in a communal area and the support worker invited respondents to speak to us one at a time.

We were supported by other members of the support groups who kindly acted as translators where necessary.

This research would not have been possible without the support of the following local organisations and we are indebted to the help they provided:

- Angelic Network
- Shifa
- YMCA East Surrey
- Surrey Minority Ethnic Forum

Summary of Key Findings

Lack of face-to-face appointments was a problem

The majority of respondents felt confident enough to have a basic conversation in English when face-to-face, however found it more difficult to speak over the phone. This was in part a language barrier as a speaking and listening down a phone line made it more difficult for our respondents to feel understood and to understand what a health care professional or clinician was telling them.

While many felt they could communicate in English, they would have problems understanding what was required of them. For example, they would be able to tell a doctor what they were experiencing, but struggle to understand the doctor's advice or what the next steps in the process would be.

While many of our respondents had access to a personal mobile phone, some would require support from a family member or friend if they got a call that required them to speak in English. For some of the women, this was a privacy issue as it meant a husband, or a child had to help them over the phone

Online services were a significant barrier

Accessing services online, either through a computer or other smart technology, was cited as an obstacle for many of our respondents. Nearly all those we spoke with had minimal access to the internet, either at home, through smart phones or through computing classes provided by community organisations. The primary obstacles were online forms for accessing GP practices and with video conferencing for appointments. Many of the respondents we spoke with did not consider themselves to be computer literate. Whilst they were getting support from community groups, they still relied heavily on support from family and others to access services adequately.

However, many of the respondents informed us that they were unable to access health services or book a primary care appointment online. For some this was down to challenges with reading and writing in English, for others, the websites themselves proved to be difficult to navigate – particularly the case with primary care appointments.

While the younger respondents were all confident with their computing skills, only a few told us that they search for information about health online. Those respondents who used the internet were more likely to look up their condition or ailment to find solutions rather than to look up services to seek out help from.

Support from family and network was key

Our respondents told us the most common source of support and help was through their families, their friends, and their wider network. The women from the support groups relied upon their husbands and children to help them translate and to use digital platforms to access care.

Our younger respondents were resident within a housing association and had each been assigned a member of staff known as a ‘key worker’ to help them navigate their way. These key workers were instrumental in guiding the young people to the right services and in obtaining appointments.

The support groups themselves were vital sources of information and offered a range of services such as English language and computing classes.

Translation services were known, but not freely offered in primary care

Translation services were widely known among our respondents and those who had used them had positive feedback. However, very few had been offered or had this service provided in primary care and our respondents would welcome more information about what options are available to them.

There was less knowledge of translation services being available in primary care . In most cases where respondents required translation support, they would ask a family member or friend to support them.

In some cases, respondents were reliant on staff members in healthcare organisations who could speak the appropriate language to help them.

Booking primary care appointments was an obstacle

Booking primary care appointments was a challenge for all respondents. Most of our respondents had limited capabilities in accessing the internet so were unable to use the booking forms on GP practice websites. Some had tried to book in person but had been told that they should use the booking system on the website.

The majority of respondents would use the telephone to get a primary care appointment. However, this process was a large frustration for many, with respondents calling at the practice opening time to find themselves in a long queue.

Financial circumstances also had an impact

Many of those we engaged with were from lower income households which placed a strain on their ability to access services. Parking fees and taxi fares were expensive for those attending regular appointments. Others noted how they couldn’t afford to miss work to attend appointments.

Key Themes

Accessing primary care appointments

Above all, our respondents told us that they prefer face-to-face appointments as they were able to understand and communicate better than over the phone:

> "It's so hard to get appointments and I can't understand the website. I can only get appointments over the phone - I need to see someone face-to-face then I can understand better." **232093.**

Family support is vital

One of the more consistent themes throughout our conversations was the importance of family and social networks in providing support and information and, in some cases, being the only means through which someone could get help if they needed it.

Spouses and children were commonly cited as potential translators to liaise with healthcare professionals and clinicians and also support for accessing appointments and services by means of computers and smart technology.

Respondents relied on family but acknowledged that spouses and children were not always readily available:

> "With my English being limited, online is difficult for me. When my husband or children are around, they can help me do the online booking but if they are not then I can't get an appointment." **232097**.

> "Language is a little issue for me. My husband can help me, but he is always working. Sometimes kids are at home, and they can help. I can speak ok but reading and writing is difficult." **232108**

There were also examples of people receiving support for long term conditions who were reliant on family to help, leaving them at risk:

> "I am diabetic and have blood pressure problems, so I need to see a doctor. If the doctor calls or sends a letter then my husband helps me to understand. If I have no family around, then I would need to wait for help." **232065.**

Family was more than just support for translation and accessing services. For many that we spoke to, their network of family and friends was their primary source of help for health matters, particularly for those who knew clinical professionals:

> "When I have had a concern, I wouldn't say I would visit GP in first instance. I usually Google first but want several opinions and within our family and friends' networks there are medical professionals. I would prefer to ask them, it's just the way I feel. One of our friends is in pharmaceuticals and I would always check with him. I would not go and see my pharmacist in our local chemist, it's just not necessary when I can call our friend or family member." **232015**

The pandemic placed a heavy strain on some individuals who relied on their family to help them navigate the care system. Restrictions on numbers of people attending appointments has meant that people who would prefer to have some support for language and interpretation are unable to do and are left managing their health by themselves:

> "I went to my GP with a coughing problem. I had Covid three months ago and the doctors just tell me this is why I'm coughing. But it doesn't help. They just told me to go to the walk-in centre. But they didn't do anything either. Didn't do any scans or anything.
>
> I wanted to take my husband with me to help as I don't speak English very well, but he wasn't allowed with me. I need his help to translate with my appointments.
>
> I'm treating myself with cough medicine to manage the problem. I don't know what to do if it gets worse." **232069**

We also heard from people who had recently arrived in the UK, to provide care support for close family, but were not aware of what support was available for themselves:

> "I arrived [three months ago], I have no idea of the NHS. My sister is pregnant, so I came here to support her. I don't have a GP and haven't used any services. I don't know about who to call or where to go. I was told I need an NHS number before I can speak to a doctor." **158794 [no CQC Ref]**

One respondent who required a translator to communicate with us, expressed that being dependent on help from her husband left her with no privacy:

> "If the doctor calls me or texts me, I need my husband to translate. There's no privacy. If I need any help, my husband needs to be there. I'm alone at home in the day, if I need medical help, I have to wait for my husband to come back. **" 232030**

Sadly, families were not universally supportive. In one case, where a respondent had been in an abusive relationship, the importance of the GP came more into focus:

> "I was being abused by husband and I didn't know where to go. I don't speak English so well, so it was difficult. I went to the GP, and they were brilliant. They sorted an Arabic translator, they helped get me to a refuge. The GP saved me. " **234321**

In this case, translation services were vital in ensuring the respondent was able to find a place to be safe.

Family support was impacted by the pandemic restrictions

The pandemic restrictions also impacted people receiving acute care, leaving those who were unable to communicate cut off from the support of their family:

> "My mother-in-law had a mini-stroke, and we didn't know for a long time where she was. She wasn't allowed anyone with her, and nobody called us - she couldn't speak English and couldn't communicate with anybody. " **232090**

While there was understanding why the restrictions were in place, there was frustration that these restrictions were barriers to those who couldn't communicate to receiving the right care. The following story highlights how important it can be to involve family members in the care of their relatives, particularly those with complex needs:

> "My mum had a stroke, and we took her to hospital. She was at home alone; she didn't know what happened. It was only when my brother saw her later that day, that he noticed it in her face. He then called the GP, who referred her to A&E. We weren't allowed to be with her during the triage process. This was not the height of the pandemic it was last year when things were better. My mum had no means of communicating without her family's help. They got a translator, but she couldn't understand. They were speaking Urdu to her, but she's not educated, how is she supposed to understand? Everybody's got their own language. There are different variations, different accents. My mum is at home, she didn't have a formal education, so she is not used to how different people speak. Also, the translator they offered spoke to her over the phone. She has a hearing problem so she couldn't hear. But she couldn't tell anyone. My mum is diabetic, and she couldn't communicate. She needs to eat regularly, and she didn't get food

> when she needed it. She collapsed and fell on the floor before they brought her a sandwich. I'm out in the corridor for 6 hours waiting. No one's talking to me. I want to know what's happened to my mum. I want someone to tell me what's happened. All they kept telling me was that she is getting good care." **232034**

In cases, such as the example cited above, individuals did not see themselves as carers and did not want to register as such as they felt this was tantamount to asking for financial support which they did not need:

> "I used to go to Frimley Park as I was the sole care for my father who has now passed away. They were great with him but I had to go to all his appointments with him to help him because he couldn't understand." **232112**

> "We all look after her, but none of us are her carers. We don't claim anything or get any support". **232034**

Support from community organisations

We spoke with several people who had travelled to the UK as refugees who were grateful for the support from community services in guiding them:

> "We have teachers [in the support groups] who can help us or our friends. Sometimes we're confused when people need help about diet or with their blood pressure. We don't always know where to tell people to go.
>
> The best support we get is for computers. Learning how to use computers helps to do everything else". **232046 [refugee]**

For others who came as migrants and had been resident in the UK for a substantial period of time, these groups represented the opportunity to participate in the wider community:

> "I found out about [the support groups] through my family connections. They have helped me get out of the house and do different things. I am learning how to read English better and also how to use computers. I've been in [the UK] for 19 years and this is first time I am getting support like this". **232097**

While there was access to the right information, the respondents acknowledged other barriers to accessing help:

> "I came here 2 years ago. We were given good introductory information about doctors and services. I know about 111/999 but I

> don't have the confidence to use them. I can't use services online though". **232049 [refugee]**

Some of the younger refugee respondents were around 17 or 18 years old and relied heavily on their key workers, who fulfilled the role of a surrogate family and helped them access support:

> "My key worker books all my appointments. I tell my key worker if I have a problem. I wouldn't ring [the GP] myself". **234301 [refugee]**

There was also an acknowledge of the importance of educational services to provide advice around living a healthier life to prevent a need for healthcare interventions:

> "I am not good at cooking - I'm not much of an eater. The college recommended [that we look up how to eat healthily] and told us about how to eat properly. That we should eat more fruits and so on. I use the internet to look things up - I have looked up healthy eating on the NHS website". **234320**

Access to translators

Most of our respondents were aware that translation services were available, however only a few had used them.

There was good feedback from those who had used translation services in hospital settings:

> "Ashford Hospital the translation services are very good, St Peters are OK. You need to tell them a long time before to give them enough notice". **232097**

> "I had a blood test at the hospital and it was ok. My key worker was with me but I wasn't sure what was happening. But I got advice from a translator over the phone and that helped me to understand". **234306 [refugee]**

There were a few circumstances where primary care staff were able to support patients in other languages however this also had its drawbacks:

> "There is a nurse at my GP who can speak Urdu, if she is not available then I am unable to get an appointment. If I can't get an appointment, then I just leave it [and don't follow up]". **232027**

“My English is not good, the lady who works at the GP helps me if she is available. If she isn't available, then I can't get help - this upsets me”. **232029**

Remote access and digital barriers

The introduction of remote appointments created a series of challenges for our respondents as many told us that they didn’t have enough knowledge to access services through the internet. While most had access to the internet either through a home computer or through a smart phone, few had the confidence to use it and relied on support, often from their children:

“With my English being limited online is difficult for me. When my husband or children are around, they can help me do the online booking but if they are not then I can't get an appointment”. **232097**

I need help with language, and I don't know how to use the internet. My son and my niece also help me when my husband is busy”. **232030**

Respondents found themselves in a difficult position, as they needed advice and support, and were frustrated by their inability to access it:

“I missed appointments because I didn't know how to use Zoom. They kept sending me emails - Zoom or Teams, I don't know these things. They sent a link, and I didn't know what to do. My daughter had to call to tell them they needed to call me and when I would be home so that I could speak to a doctor.

My daughter showed me video calls but it was very hard. It took so long to learn English to communicate, now I had to learn something else too. Even after this, I didn't know how to do everything. They are asking me to show them something, to press something. Everything has its own password that we have to remember, I don't know how to use all of it. Once I was on a call and they were asking me to do all these things - I started crying, it was so stressful”. **232043**

The general shift towards online services (during and following the pandemic), had left some people feeling excluded and vulnerable to further problems:

“During [the pandemic] it was very stressful. Everything was online and I couldn't do it. Couldn't do shopping, couldn't make appointments. I lost my job too and needed to apply for

> compensation or whatever it was called - I had to do this online. I didn't understand, I started to write but then the form disappeared, and I lost everything". **232043**

Financial barriers

The respondents we spoke with were predominantly from low-income households leading to conflicts of choice between one's health and being able to financially support oneself.

For some, language presented barriers to accessing employment opportunities to enable a healthier life balance. Some respondents with long-term conditions, were left struggling in jobs that they needed to support themselves financially however these jobs also impacted their health.

> "It's difficult trying to keep a job and look after your health. I was diagnosed with an irregular heartbeat and mild Covid. it was affecting me because of my heart condition. I have had follow up appointments and I have tablets. The GP gave me a heart monitor. It was difficult to get back to work [after Covid]. I was still feeling weak for a while afterwards. The people at work wanted me to go home, but I needed to work to support myself". **232073**

We also spoke with people who had health struggles because their employment opportunities were limited due to their limited language skills:

> "I have arthritis in my knee - it gets painful to stand for a long time. I need to get a new job because I'm on my feet all day. Reading English is especially difficult for me, so I don't know how to use computers". **232102**

One respondent who was unable to work due to long term health problems, however a breakdown in communication with her GP had left her in a difficult situation:

> "I have had some problems with my GP providing me with a fit [to work] note. I have some [long-term] health problems that mean I can't work. I have a problem with my leg and with my eyes. I am single mum of two and without this note I am now getting pressure from the job centre to find work. The GP used to provide the note for me but now they won't, and I don't understand why". **235302.**

Conclusions and opportunities for further research

It is important to highlight here that this research was only possible with the collaboration and partnership of community groups, whose support had helped many of the respondents to develop their language computer literacy enabling them better access than others. These groups are often key in bringing together isolated and vulnerable members of the community.

We would propose a deeper exploration of the cultural issues barriers involved. For example, many of the community groups were supporting women from Pakistani backgrounds where the older members of the community did not have a formal education and therefore lacked literacy skills in their mother tongue. Similarly, the family structure within this community creates a certain dynamic between men and women, particularly women following marriage, that impacts the means through which they engage with the wider society. While there was seemingly no restriction in the women's communication with us, if we are to better understand how we can facilitate better outcomes for people from different backgrounds, there needs to be a deeper understanding of the cultural influences on people, their world view, and ultimately their view of health and health intervention.

A model of continuous engagement – reflections

Identifying community leaders

Networking with place leaders and key community groups and their leaders was key in identifying and reaching respondents. Through an initial mapping exercise, we identified areas in Surrey where there were higher numbers of ethnic minority communities. We drew on community contacts already known to us as well as new community groups. By being in the right place within the community, and making contact via the leaders, we were able to establish new relationships with the new groups.

Support of the groups

We could not have engaged with some of the respondents without the support of the groups. For example, some of the respondents only socialise in these groups and are not on any social media platform, so we wouldn't have been able to locate them. The group leaders also enabled us to have conversations with a group member who interpreted for us. This was invaluable to us and ensured we got good in-depth insight.

Flexibility in our approach

We had top line guide questions and prompts but, overall, we approached the engagement as part of an 'organic' conversation and adopted the 'SAIL' approach (Surrey Appreciative Inquiry & learning) asking open ended questions and recording it in the first person. This relaxed participants and led to more in depth conversations and insight.

Conversations were sometimes on a 1:1 basis, other times a couple of friends wanted to sit together and chat at the same time. We also undertook some telephone interviews in cases where English was not an issue. In one of our engagements, we carried out a focus group due to the number of people.

Incentives

We incentivised each respondent with a £10 voucher for their time and each respondent was very grateful. The groups were happy that the respondents were participating and contributing to the project.

Reaching men

The groups we visited were support groups held during the day and attendees were predominantly female. This meant we reached fewer men than we would have liked through the programme of engagement. The women we spoke to reported that men were out at work during the day and as their English was better, they didn't need the support of the groups as much as women.

For a continuous model of engagement, alternative methods would be needed to reach men, e.g. in their workplace, place of worship, lunch breaks after work or through other family members.

We were able to have 44 conversations with individuals who were from a Black, Ethnic Minority background and 11 of these were identified to be refugees or asylum seekers.

Recommendations

Ongoing relationships

As part of a continuous engagement model, we would propose that a regular steering group / catch-up meeting with group leaders would be established. This would be an ideal platform through which to listen in to any on-going issues with access to services and any issues with NHS care providers.

We would also propose that the groups we worked with are re-visited in the future to see if any of the signposting we have given them, had helped them become more informed about primary care access and self-care awareness.

Information and advice

A further recommendation would be to provide more information around patient rights, NHS infrastructure and signposting. For example, at one of the groups, respondents were unaware you could register at a GP Practice without an NHS number. Healthwatch followed up by sending the group some; "My Right to

Healthcare, GP Access cards". Refugees and asylum seekers were very unaware of the NHS infrastructure and relied upon other group members to inform them.

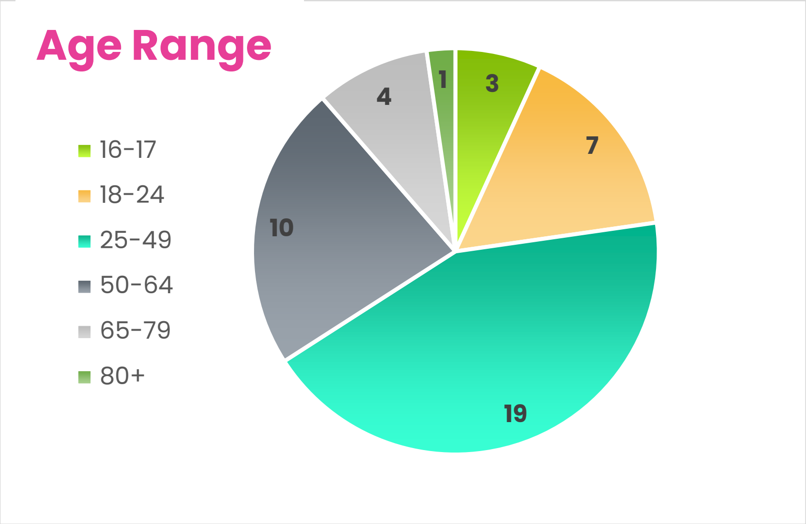
Translation

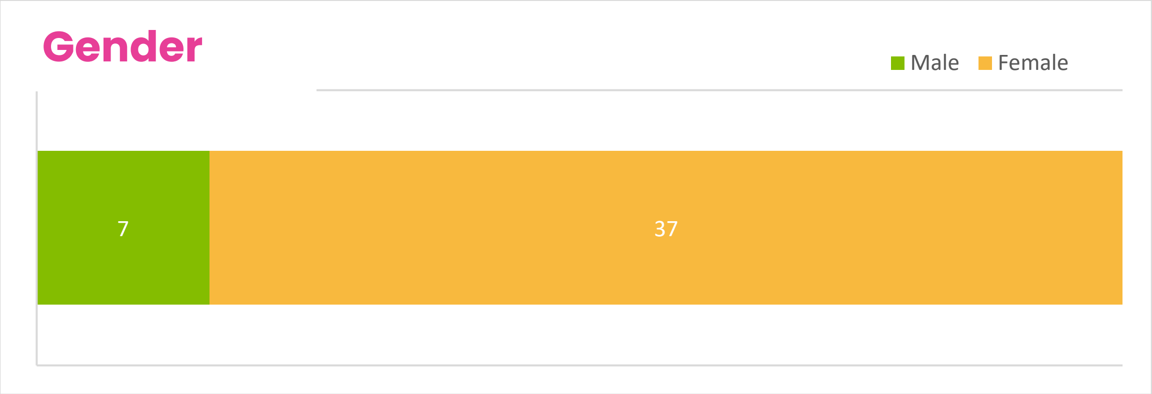
Translation services should be offered more freely to individuals who clearly need it and the services should be advertised in spaces people frequent, such as Mosques, supermarkets, support groups, schools etc.

Thanks

Healthwatch Surrey would like to thank everyone who shared their experiences with us and all the community group leaders who facilitated contact and access.

Appendix: Demographic Data





Primary Languages Spoken

- Urdu 23
- Arabic 8
- Hindi 6
- Tigrinya 4
- Afghan 1
- Farsi 1
- Tetun 1