



Patient experiences of NHS 111

Focus group findings by Healthwatch Enfield

July 2022



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Introduction

Healthwatch Enfield were approached by North Central London Integrated Care Board (NCL ICB) to undertake a series of focus groups with local people from specific communities to identify and discuss people’s experiences of using NHS 111, with a focus on using the service as a local resident with additional access needs such as disabilities or English as a second language.

Methodology

NCL ICB carried out an online survey seeking views from the wider public on people’s experiences of using the NHS 111 service. To ensure that harder to reach groups were included in the findings, Healthwatch Enfield planned and carried out four focus groups with four specific community groups based in Enfield. These included:

- Enfield Clubhouse Mental Health Support Group – 7 participants.
- One to One Learning Disability Group – 7 participants.
- Visually Impaired Enfield Residents supported by Healthwatch Enfield – 2 participants.
- Speakers of English as a Second Language (ESOL) supported by Edmonton Community Partnership – 4 participants.

The small focus groups were led by Healthwatch Enfield staff and volunteers, using intimate conversations in a safe space to gather detailed information of people’s understanding and experiences of accessing and using the NHS 111 service.

A series of questions, aligned to the online survey were used as a framework for conversations, with participants encouraged to expand on their experiences, provide more detail and share issues that may not be covered by the questions. These topics covered included:

- People’s use of the NHS 111 service, and whether it was online or via telephone.

- Awareness of the online option.
- Telephone call menu ease of use.
- Alternatives to NHS 111 if not satisfied with it.
- Staff helpfulness.
- Appropriateness of the questions asked by the service.
- Referrals to other services and whether they were the right ones.
- Outcomes of the contact with the service.

Key findings

Access

Of the people we spoke to, more than half had used or tried to use the NHS 111 service. People with learning disabilities were most likely to have used it, followed by people with mental health needs. People with English as a second language were least likely to have used the service. Key issues faced included:

- **Awareness:** There was a general lack of awareness of the service or parts of the service.
 - Several of those who were aware of the service were not always sure what it was for or how it differed or related to other health services. This was particularly the case for non-English speakers.
 - Many of those who were aware of NHS 111, know it as a telephone service and most were unaware of the online service. People with visual impairments and those with learning disabilities expressed that they were the least likely to use the online service, either because it was inaccessible due to their lack of sight, difficulties using online services, or they preferred to speak to a person to discuss health issues, rather than use an online service.
 - At least two people from the mental health support group expressed that they would probably prefer to use the online service if they were aware of it, with others preferring to use the telephone service.
 - The group with learning disabilities felt that an entirely online service would be detrimental to people's health as it wouldn't be as accessible.
 - Participants from the mental health support group were not aware that NHS 111 could book appointments for them.
- **Health service inaccessibility:** Several people from different groups expressed frustration with trying to access primary care services like GPs.
 - One person with visual impairment discussed the difficulty of having to see locum GPs on a regular basis, and how this caused a lack of consistency in their treatment, and the need to frequently repeat information.
 - At least one person stated that they had to use the NHS 111 service frequently due to a range of ongoing conditions. They often had to call 111 in the evenings and were frequently given hospital appointments or referred to A&E, which was further to travel, but usually easier than getting a GP appointment.

“I am aware that its online but cannot use the service this way. I prefer to use my phone. It is easier for me. I do not have a support worker or anything to help me with things like accessing services...”

Service usability

- **Call Menu:** Non-English speakers and those with learning difficulties found the service hardest to use.
 - Non-English speakers discussed their difficulties with understanding the questions being asked by the service, in particular how they either simply couldn't understand the questions, with expressing embarrassment about their lack of English so they don't even try to access the services (as well as other health services).
 - At least one person expressed that people on the phone can become impatient when talking to them, if they are struggling to understand, and this can put them off using the service again.
 - The group with learning difficulties felt that the call menu was 'too long' and 'annoying' and many felt that it often led them round in circles. The group also expressed that the menu sometime caused anxiety, especially in a medical emergency.
 - One participant with LD discussed their negative experience of using the service, where they spent a number of hours holding to speak to someone, only to be cut off and ending up going straight to their GP instead.
 - People in the mental health support group also felt that the menu was generally too long-winded and off putting, potentially discouraging repeat use of the service.

“It would not be practical for me to use NHS 111 online. I am not aware of any provisions for visual impairments available for me to access at my GP or at hospital appts. When I have an appt I have to arrange in advance for a support worker to come with me to guide me physically around buildings and to read signs or instructions. I cannot do this alone. There are often problems with poor, out of date or inadequate signage in GPs and hospitals.”

- **Language and culture:** Non-English speakers again expressed the difficulties they have in being understood, both by the NHS 111 service and health services in general, including their GPs). They felt there were no options for translation and interpreting services to help them out, and there were very few local community organisations to help them out. This generally made using NHS 111 impossible.

- Non-English speakers also expressed they were far more likely to go straight to A&E than try to access other services as it was more convenient geographically, although they often had to wait longer as the hospital needs to find someone who can translate.
- The issue of people looking down on non-English speakers came up several times, with sometimes even people that speak their language being seen as judgemental because they can't speak English.
- In one case, someone described a time when their father had paid people to help them fill in forms, register for GPs etc, but that the people had stolen money. They stated that this happens all the time to lots of people.
- Participants with learning disabilities felt that they often had more health issues than others, and they were not always able to read or fully understand forms and questions, so easy read version or forms with pictures would be helpful.
- A small number of participants expressed that accents of staff of the NHS 111 service could be difficult to understand, which can make using the service more difficult.
- Several participants expressed that the people from their communities were often unlikely to access services like NHS 111 because they didn't have awareness or didn't understand how the NHS works, and what services are accessible to them. Sometimes this was more of a cultural issues with a resistance to accessing health services either due to a mistrust of authority, or because their communities relied on other methods of managing their health, for example going to community leaders or elders for advice instead.
- **Staff:** Many participants expressed that the helpfulness of the staff at NHS 111 could be hit and miss. Some members of the learning disability group stated that staff were generally very understanding, but this experience was not shared by the whole group, with several haven't different experiences of less understanding staff.
 - Members of the mental health support group felt that staff on NHS 111 (and other NHS areas) were not always helpful. One participant stated "I try to be polite."

"I have used the NHS 111 service in the past and would use it again in the future. I would say the service they provide is OK and I know that everyone these days are stressed."

- **Referrals and call backs:** Only a small number of people had been referred on to other services by NHS 111.
 - When people had been referred (usually to GPs, A&E or urgent care) people generally felt the referral was appropriate. One member of mental health support group expressed that they had definitely been referred to the right service,

however another felt that their issue had not been dealt with properly, after being referred to a dentist.

- Members of the same group also expressed that usually the issue had been dealt with at the time over the phone, so there had been no need for a call back.
- **Alternatives and complaints:** Most participants said they would either try to go their GP, or straight to A&E if they didn't find the service satisfactory.
 - Members of the learning disability group said they might also ask a family member for help, or possibly their support worker or someone from the Citizen's Advice Bureau (CAB).
 - One of participants with visual impairment stated they Often had to spend a long time on the phone to their GP to get appointments.
 - Members of the mental health support group also stated they were most likely to go to their GP if they weren't satisfied with 111 service, but felt that this was often a 'post code lottery' of access. There were also strong feelings that GPs were now using Covid as an excuse for poor access.
 - Several participants of the mental health support group stated they would not always be comfortable making complaints about the service.

“My dad paid people to help us, fill out application forms, register with GPs et, but they were not always good people as they stole our money. It cost us a lot of money and we did not get proper support. This was happening all the time, to lots of people we know.”

Actions/Recommendations

Based on the conversations held during the focus groups, most of the feedback we received coalesced around the three themes of awareness, accessibility, and useability. Specifically, the following areas appear to be ripe for further investigation and/or action, and would be relevant to the upcoming NHS 111 procurement process:

- **Language:** The availability and use of interpreting services appear to be a particular block to people using the service. This is especially true for non-English speakers and those with learning difficulties. If translation services are available, they need to be advertised more widely, including through the service itself. If not available, then further investigation is needed into how this section of the community can best be provided for. Consideration also needs to be given for people who are deaf or hearing impaired, especially British Sign Language users, who may need to rely on other people to use the service, if they are not able to use the online service.
- **Awareness:** Awareness generally of NHS 111 appears to be low. Those who were aware of the service were often not aware of what the service can offer (for example booking appointments), and most were not aware that the service was also available online. Further communication/marketing needs to take place to improve awareness amongst particular communities and sections of the society

- **Service user support and staff training:** The helpfulness and effectiveness offered by staff on NHS 111 appears to be patchy, with a variety of mixed experiences. People with learning difficulties and non-English speakers seemed to have the least positive experiences. As a result we recommend the following:
 - **Training:** Additional training could be provided to NHS 111 staff, potentially supported by or provided directly by voluntary sector/community groups with lived experience to help staff with understanding and patience when handling calls from people with additional needs.
 - **Support:** The NHS should investigate the possibility of offering direct support services to particular groups with additional needs. This could be additional funding to support local community groups, but ideally specialist, trained call handlers to support people – accessible either through the call menu or possibly a new number.
- **Usability:** The call menu on NHS 111 is long, unwieldy and can put people off using the service with the potential impact of increasing pressure on other NHS services. A more refined menu, with fewer questions, and clearer pathways and potential outcomes would be preferable.

Engagement in service development and delivery

In general, all of the focus groups appreciated the opportunity to feed into this process. It was felt that more frequent, honest and genuine collaboration and co-production between local health organisations, professionals, and residents is vital to move forward and improve services. Regular community conversations about services like NHS 111 should be widely advertised and accessible. This reflects a common theme raised by local people with us over the past few months. This approach can go a long way to improve delivery of key underutilised services like NHS 111, as well as the knowledge, understanding and usage by all sectors of the community, especially amongst more marginalised communities. This in turn, may help to reduce pressure on other essential services like GPs and A&E, and improve the health and wellbeing of all residents in our local community.