

Navigating the Health Service in Grampian

Introduction and context

GREC is a registered charity based in Aberdeen, taking a leading role in advancing equality across North East Scotland – including Aberdeen City, Aberdeenshire and Moray – since 1984. GREC focuses on tackling prejudice and discrimination, celebrate diversity, build positive community relations, and provide evidence to change policy and practice through a range of services and projects.

In line with this work, we were asked by NHS Grampian to conduct a series of focus groups with members of ethnic minority communities in North East Scotland. Based on NHS Grampian's language service request data, it was decided eight focus groups would be held, each facilitated in a different language: Arabic, Bengali, Cantonese, English, Farsi, Lithuanian, Polish, and Russian.

The key focus areas included:

- Current understanding of NHS Grampian services
- What is not understood?
- Preferred method of disseminating information about NHSG services
- Where information is currently found or looked for

A facilitator guide was provided by NHS Grampian, outlining the topics, questions, and key information, which was shared with the facilitators and interpreters.

As the Scottish Government notes in the 'Anti-racism in Scotland: progress review 2023', structural racism and discrimination exacerbate health inequalities for ethnic minority communities. Especially given the increasing inflammatory rhetoric faced by migrants and people from racialised minority communities in North East Scotland, rhetoric which often blames minoritised people for the issues faced by the healthcare system, it is vital that NHS Grampian continues to engage in a sensitive, sustained, and accountable manner with all the communities it serves.

Methods

Participants were recruited through a call sent out through GREC's network of community connections, interpreters, and partner organisations. An infographic explaining the focus group, translated into each of the target languages, was sent out by email, along with a QR code and link to a registration form. On the day of the focus group, a link to the Zoom meeting was sent to at least five registrants for each language

group, prioritised on the following basis: first, registrants who we recognised to be legitimate and eligible for the focus group; second, individuals to whom we had sent invitations directly; third, registrants in the order they had signed up. Significant challenges with ineligible registrants arose, which will be further described in the Challenges section. In order to supplement some of the language groups that had very few eligible participants, additional in-person focus groups and individual interviews were scheduled with a small number of people from Farsi- and Polish-speaking communities. These sessions followed the same facilitation and presentation structure as the focus groups. In total, we heard from 37 participants.

In the meeting, each of the language groups was separated into breakout rooms. Each group had one facilitator from GREC and an interpreter (except the English-language group, which had no interpreter and two co-facilitators, one from GREC and one representing the NHS). Facilitators used the guide provided by NHS Grampian to direct discussion. Notes were collected using a Menti presentation for each group and the facilitators' own notes. The slides on the Menti presentation followed the questions in the facilitator guide. Q7, *Navigation Scenarios*, was reformatted such that participants could select one of four responses to each health problem. This was done because Menti limits the number of options to multiple choice questions.

After the focus groups, the Menti presentations and notes were collated for analysis. Participant responses were coded using content analysis with inductively generated codes to highlight key themes from the discussions. Due to the relatively low sample size, the questions collecting quantitative data are not especially reliable. However, plots visualising the data from those questions have been provided to supplement and contextualise the qualitative responses. Quotations were given in English, either by participants directly or by the interpreter of the speaker's group.

Demographics

There were 37 participants in total: 18 women and 19 men. The largest age group was 25-44 (29 participants), followed by 45-64 (5 participants), and 18-24 (3 participants). 17 participants had lived in Scotland for 2-5 years, 15 for over 5 years, 3 were born in Scotland, and 2 had lived in Scotland for 6-23 months.

Participants were asked to write in their self-identified ethnicity. These responses were then indexed to the categories defined by the Scottish census. Of the participants who described their ethnicity, 8 were 'Other White'; 4 were 'African, African Scottish, or African British'; 3 were 'Arab, Arab Scottish, or Arab British'; 3 were 'Chinese, Chinese Scottish, or Chinese British'; 3 were 'Indian, Indian Scottish, or Indian British'; 1 was 'Gypsy/Traveller'; 1 was 'White Polish'; 1 was 'Pakistani, Pakistani Scottish, or Pakistani

British'; 1 was 'Other Asian'. Some participants' answers did not neatly index to the Scottish census categories: 3 wrote in 'Syrian' and 1 wrote in 'Persian'.

Not every participant completed every question in the demographic survey. Additionally, because participants were asked to complete the demographic survey at the beginning of the session, some ineligible participants were included in the demographic collection. Where these entries could be identified, they were removed. Because responses to the Menti questions were collected anonymously, that data cannot be disaggregated by demographics.

[Responses](#)

Understanding of the NHS

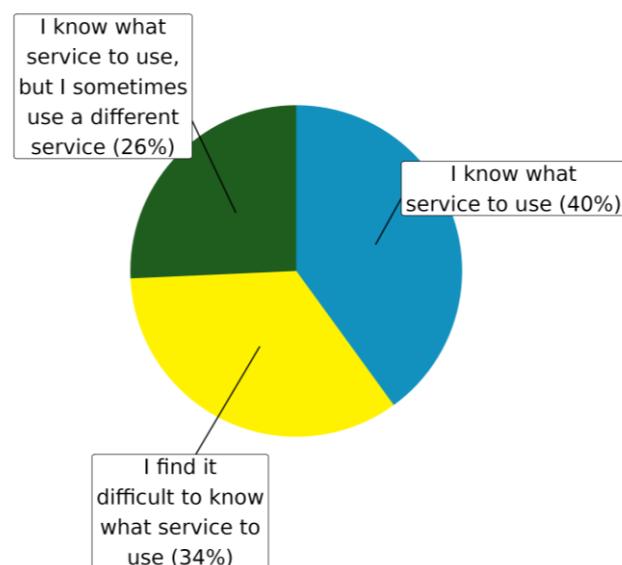
When asked *What comes to mind when thinking about the NHS?* without further prompting, participants responded with a number of positive and negative associations. The most common positive associations were **free of charge**, **comprehensive health service**, **reassuring and always there for you**, and **universal care for everyone**. The most common negative associations were **long waiting times**, **services under pressure**, and **language barriers**. In this question, positive responses greatly outnumbered negative responses. However, throughout the course of the focus groups, most discussions were centred on negative experiences the participants had had with NHS services.

NHS services being free was the most common theme and was brought up in nearly every group. Many participants' first association with the NHS was 'free services', 'free at the point of use', and 'free healthcare'. No mention was made in any group about the immigration health surcharge. Without information about migrant participants' specific visa conditions, it may be that none of the participants have been required to pay the surcharge. However, it is also possible that NHS services are seen as separate from the immigration processes that inform much of how people with limited leave to remain interact with public services. This ties in with another theme that came up in several groups: **universal care for everyone**. Participants described the NHS as 'something unique that reflects fairness and care for everyone', reflecting 'equality for all' and 'accessibility for all'. Some individual participants described the NHS being important for the community and a source of national pride, suggesting the universality of the NHS corresponds with a sense of wider belonging. The second most common theme, **comprehensive health service**, reflected the participants' understanding of the NHS as a system to which they could turn with whatever health condition they were experiencing.

The most frequent negative theme was **long waiting times**. This reoccurred throughout the other sections, especially Barriers and Experiences. Waiting times were associated with frustration, worsening conditions due to delayed access to treatment, and poor mental health. Several participants tied **long waiting times** to another theme, **services under pressure**. They acknowledged systemic issues such as underfunding as a contributor to the pressure the NHS faces and the resulting long waiting times for services. Some participants also contrasted their association of the NHS as organisationally slow and frustrating with NHS staff as hardworking.

Fig. 1 illustrates the participants' responses to Q2, *Which one of the following statements best describes your understanding of which NHS healthcare service you should access, if you are ill or injured?*. While many people did feel confident about what services they could access in the event of illness or injury, a large proportion were unsure or found it difficult to know. Although there was not a focussed question about why some people use different services than the intended

Fig. 1: Which statement best describes your understanding of which NHS healthcare service you should access?



ones, participants in some groups described preferring to avoid going to the GP with issues because of poor communication, long waiting times, and a lack of trust. These participants discussed preferring to visit pharmacists, with whom they had better relationships, or using self-care to treat conditions at home. Some participants also described not using ambulance services because of experiences with long wait times and language barriers when on the phone with emergency services.

When the groups were asked *Can you tell us which healthcare services are provided by the NHS that you would turn to or use when ill or injured?*, the most common response was their GP, despite many groups describing significant issues with access as above. The next most common response was NHS 24 or 111, followed by Emergency Department or A&E. After this were a number of other NHS services such as pharmacies, 999/ambulance services, and dentists, and 'hospital'. Many participants commented that the service they would seek help from depended on the issue they were facing. However, for general support, advice, and signposting, the most common response was to contact the GP or NHS 24.

Figs. 2 and 3 illustrate the groups' responses to the service awareness exercise. As Fig. 2 shows, most services are generally well known, especially the Scottish Ambulance Service, dentist, and optician. However, the Minor Injuries Unit and Sexual Health Services were much less recognised, with over half of respondents marking either "Unaware" or "Unsure" of those services. The relatively high proportion of "Unaware" responses to GP practice is unusual, given the number of groups who discussed their experiences accessing GP services. This may be because confusion around what the question was asking, or suggest that GP services are a significant matter to those who can access them, but not as widely understood as more universally recognisable systems, such as the Scottish Ambulance Service. Fig. 3 collates the responses to every service, then separates the data out by language group. Most groups marked an overall awareness of NHS services of around 75%. The English-language group, while holding to this pattern, had significantly fewer "Unaware" responses, and correspondingly more "Unsure" responses. The Cantonese-language group had a much higher rate of "Unaware" responses than the other groups. While this data is not necessarily representative of the wider ethnic minority communities in North East Scotland, it could suggest a need to further examine how NHS Grampian extends access to Cantonese-speaking communities specifically.

Fig. 2: What is your awareness of these NHS services?

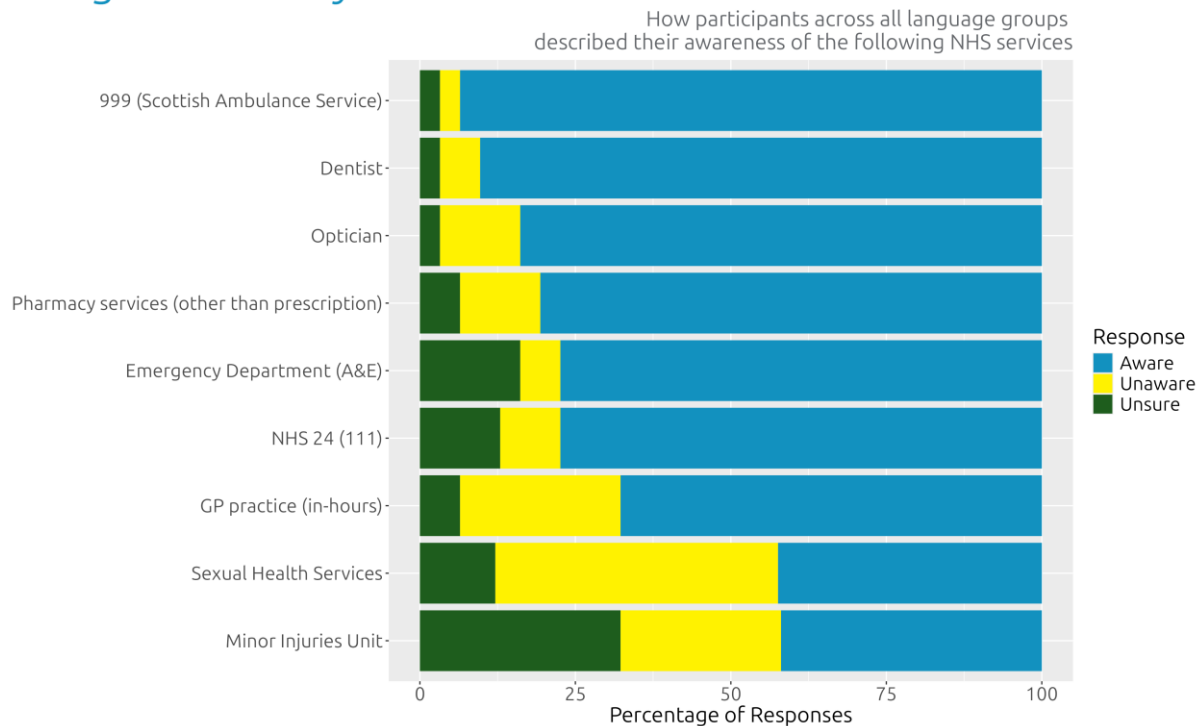
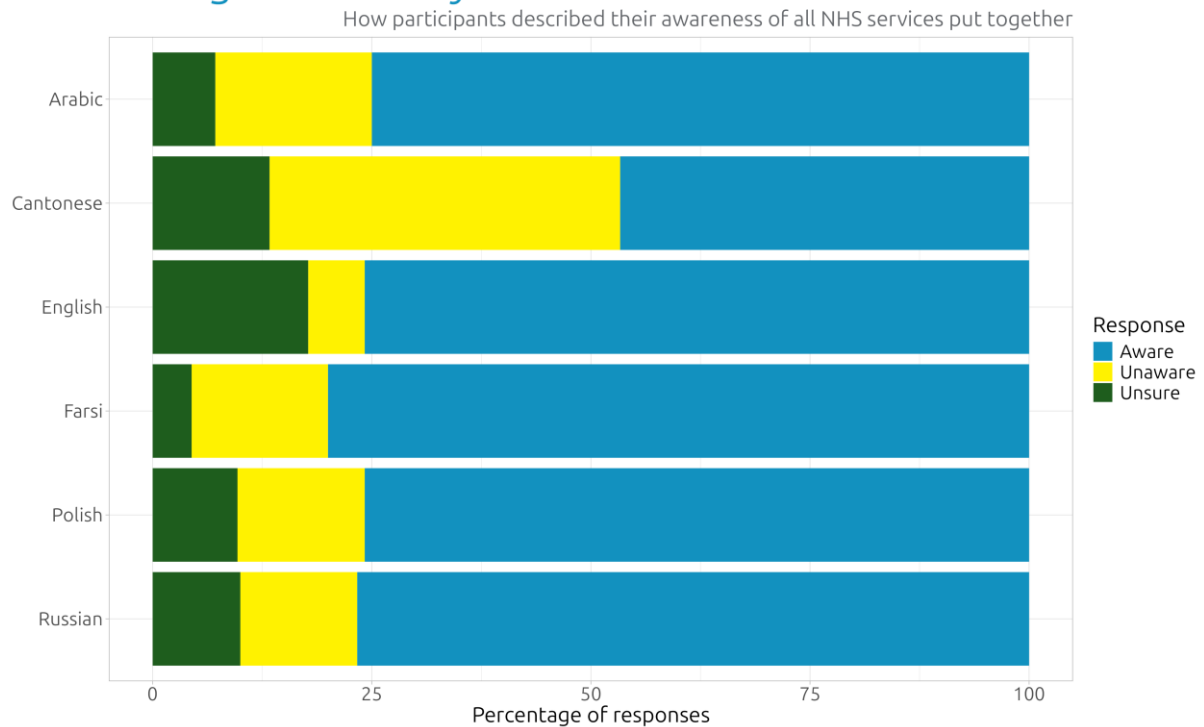


Fig. 3: What is your awareness of NHS services?



Barriers and Experiences

Participants responded to Q4, *If you or a family member were ill, and looking for advice, medication, or treatment how would you decide/choose what service to use?*, with a range of responses. Most were either conditional on the circumstances, such as the urgency of the condition and time of day, or based on advice from others. Several groups mentioned their first choice of service depended on what was open, such as contacting their GP in-hours or NHS 24 during out-of-hours. When considering the urgency of the condition, participants across various groups stated they would go to a pharmacy for minor issues, GP for non-urgent but more serious issues, and either A&E or 999 for emergencies or serious injuries.

Several participants mentioned preferring pharmacies over their GP, due to a lack of waiting lists, better communication, and a more established relationship of trust with pharmacists, even when they were perceived to have less power to treat conditions than GPs. Some also had poor experiences with A&E departments and Scottish Ambulance Services, due to significant waiting times, incorrect diagnoses, and witnessing people in severe distress not being attended to. When participants discussed looking for advice for which service to use, the most common sources of advice were GP clinics, despite the issues described above, with pharmacies, friends and family, and web search or ChatGPT mentioned about equally.

When asked *Is there anything that makes it hard/difficult for you (or people you know) to use NHS services?*, most participants' responses fell under one of the following themes: **long waiting times**, **language barriers**, **availability**, **transportation**, and **not being listened to**. The English-language group was the only one in which some participants said there were no barriers to accessing NHS services, although other participants in that group described several issues that made access difficult.

Long waiting times was the most frequent issue participants described. This included time waiting for a GP appointment, time waiting for a call back from their GP, waiting lists for specialists, time waiting for an ambulance, time waiting at A&E, and delays for referrals, tests, and operations. The consequences of these long waits included progression of conditions, worsening mental health, reduced trust in the NHS, and avoiding NHS services in future. As one participant told us, 'There are bottlenecks to accessing the right service... the same situation once you are on waiting list. Even if the problem is being amplified or getting worse. They just say wait.'

Language barriers were a recurrent issue in the focus groups, including the English-language group. Specific issues included difficulty understanding Scottish accents, not having interpretation available prior to scheduled appointments (such as when calling the GP reception to book an appointment), difficulty describing a situation to 999 call handlers, difficulty finding the right service, having to facilitate between the healthcare

system and family members with a lower level of English fluency, and not being understood by healthcare professionals. Even when interpretation was available, some barriers still existed. Participants described feeling uncomfortable sharing medical details with interpreters, having to work around restricted appointment times because of the need to schedule an interpreter, and difficulty describing complex medical issues. Phone calls were a significant point of difficulty for people experiencing language barriers: when phoning NHS 111, 999, or GP receptions, participants across multiple groups described having to answer a long series of questions in English before being able to access a service where interpretation could be provided, which in some cases was not possible.

The **availability** of NHS services was the next most common issue. This included difficulty getting through to GPs on phone lines (having to call between 08:00-09:00, or not being connected at all), services closing at 17:00 on weekdays making scheduling appointments difficult, the inability to see GPs in person, shortened appointments, and struggling to access mental health support. Even when on a waiting list, participants described issues accessing the services they needed: 'There are bottlenecks to accessing the right service regarding the same situation once you are on waiting list. Even if the problem is being amplified or getting worse. They just say wait'.

Closely tied to issues with availability, **transportation** was another common theme. Both transportation time and cost were listed as specific issues across several groups. As was later discussed in the Communication and Engagement section, there was a desire for more localised, easily accessible services.

Not feeling listened to manifested in both interpersonal and organisational interactions. Some participants described 'feeling dismissed or not taken seriously' by healthcare professionals, doctors who did not listen to questions, or experiencing a lack of interest and care. Others experienced issues on a management level, such as managers not listening or being unhappy with feedback. Some participants commented they did not know how to provide feedback on their experiences with healthcare services, leaving them feeling voiceless. Some participants described cases in which not being listened to or being misunderstood led to incorrect diagnoses or inadequate treatment, ultimately resulting in worsening condition.

Another common issue participants faced was being redirected through multiple NHS services, especially back and forth between their GP and pharmacies, who would each refer participants to the other. These cases required a significant amount of time and energy by the participants to resolve, which they felt was not worth the level of care they received.

Responses to Q6, *Have you ever avoided seeking help because you felt unsure what to do?*, were divided. About half the participants stated they had not avoided seeking

help, including the majority of the English-language group. Others gave reasons why they had avoided seeking help despite knowing the recommended service, such as feeling embarrassed by some conditions, avoiding stigma, not knowing if they would be treated well, being conscious of the strains on NHS services, being unable to make an appointment with the GP, or feeling GP services were too impatient and hurried. A few participants from most groups stated they had avoided seeking help because they did not know where to go, resulting in delayed treatment or relying entirely on self-care. In other questions, it emerged that some participants sought private healthcare because they weren't aware what services were available through the NHS (as will be mentioned in the Communication and Engagement section), or waited until they were in their home country to complete certain screenings and procedures (as will be mentioned in the Screening and Medical Test Invitations section).

Navigation Scenarios

Figs. 4 and 5 illustrate the participants' responses to Q7, *Which healthcare service would you be most likely to turn to first for each of these health problems?*. As mentioned in the Methods section, because of constraints with Menti, our data collection platform, participants could choose from only one of four options for each scenario. Most participants had a strong understanding of where they should go for the example health problems, especially flu symptoms and back pain. Head lice and toothaches were the only health problems for which more respondents chose a service other than the NHS recommended option, NHS 24. Several respondents mentioned that because they did not have school-age children, they had never had to deal with head lice in Scotland. When participants chose a service other than the ones recommended by the NHS, the most common choice was Self Care, which was commonly selected in the head lice and toothache scenarios. This was followed by GP, selected in the head lice and blurred vision scenarios, and Pharmacy, chosen in the vomiting scenario. Emergency Department was chosen as an alternative service in the back pain and toothache scenarios. 999 was only chosen as an alternative service once, in the vomiting scenario.

Fig. 4: Do you know where to go to for each of these health problems?

Whether participants across all language group chose the NHS recommended service or a different service for each health problem

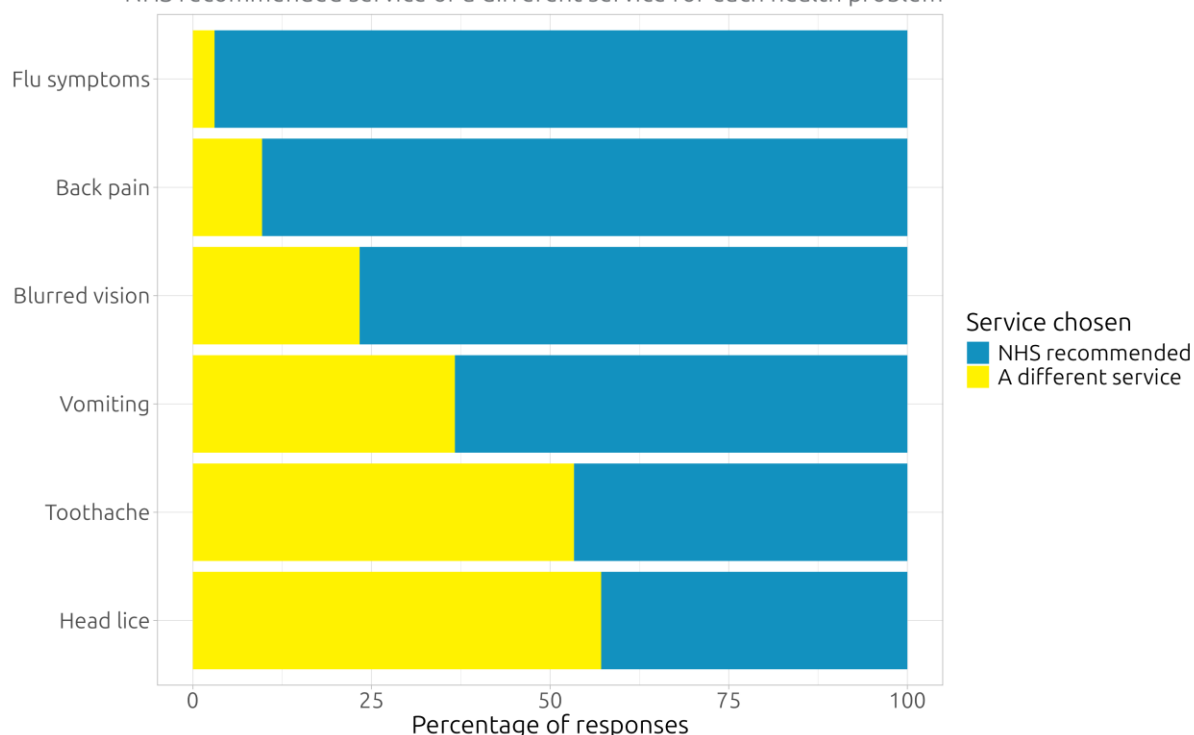
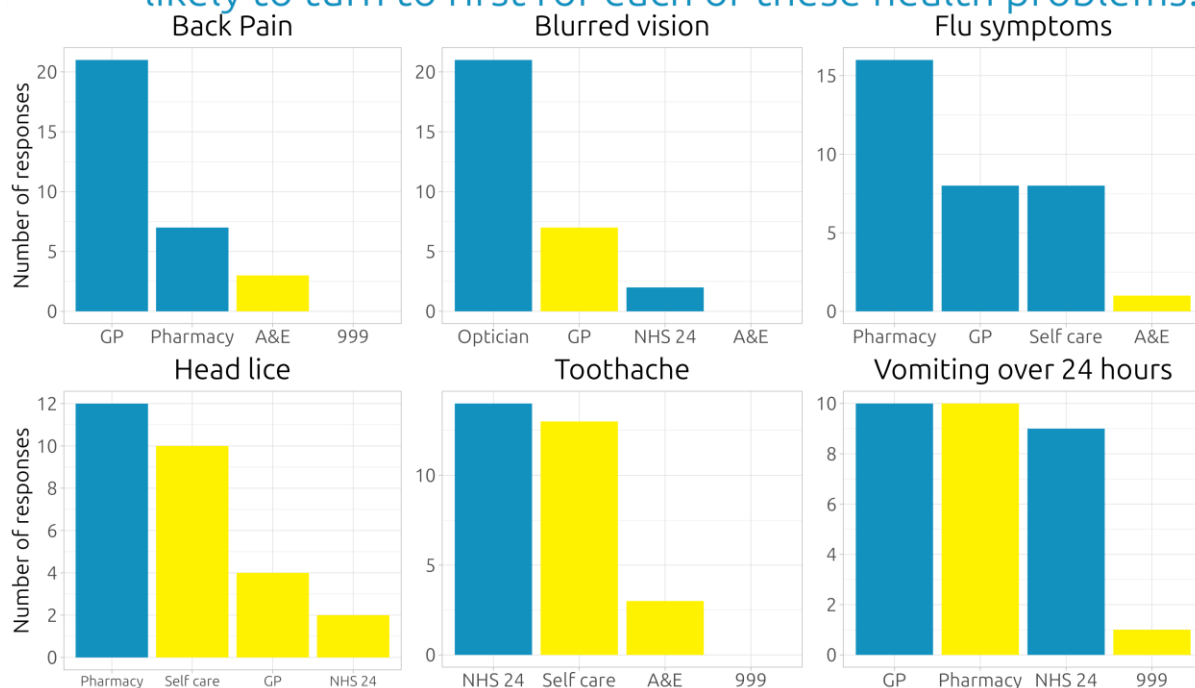


Fig. 5: Which healthcare service would you be most likely to turn to first for each of these health problems?



Screening and Medical Test Invitations

The participants gave a wide range of responses to Q8., *When you receive an invitation or letter for screening, such as bowel or cervical screening, or a medical test, what helps you decide whether to take part?*. Many participants stated they would attend whatever test they were invited to, which was coded as **trust in the system** alongside responses such as ‘I check if I trust the source’ and, succinctly, ‘Trust in NHS’. One participant told us of a family member that attends screening appointments and medical tests when they are in their country of birth because of their trust in that country’s medical system. As this example demonstrates, people's willingness to attend medical invitations is strongly based on trust and perceived competence.

Trust ties to two other themes that emerged from this question: **advice from trusted medical practitioners** and **advice from network**. Some participants told us that they would bring letters to pharmacists, GPs, and community health workers they trusted in order to better understand the test and to seek their advice on the necessity of those tests. Others would bring those letters to family members and work colleagues to hear their opinion. This can be an emotionally charged process: one participant told us, ‘When I receive invitation or screening something I feel so nervous so I seek advice from my superior whether to take part or not’. Test and screening invitations are highly affective materials which can induce feelings such as fear, anxiety, and embarrassment around both the procedure and potential results. Trust, for some participants, is a way of negotiating these emotions.

The only topic that came up more often than trust was knowledge, coded as **understanding the purpose and importance of the test** and **understanding benefits and risks**. These themes emerged distinctly but closely related. Participants across most of the groups said that both having information about the test and understanding its potential benefits and risks were important factors in their decisions. Responses such as ‘The reason for the test, potential benefits, and advice from my GP or family usually help me decide’, ‘My current state of health, Reasons behind the intentions and what I stand to gain’, and ‘Understanding what the test is for/Clear explanation of what the screening checks for/Knowing the benefits any risks or downsides’ illustrate how participants consider both how the test is relevant to their current circumstances and what the potential consequences of the test are in making their decisions. Other responses highlight one or the other, such as ‘understand why it matters/feel it’s relevant to them personally’ and ‘what are the benefits’. While some participants considered both benefits and risks, as the above quotes also demonstrate, potential benefits are a more important factor for most people. Invitations that are seen as both relevant and beneficial are the most likely to be accepted. Some participants expressed a desire for invitations to be sent out with explanations in their primary language.

Others suggested a video explainer would be the best method of communicating information about the test.

As well as the perceived importance of the test, the relevance of an invitation is related to what some participants described as their **current health condition**. Across multiple groups, participants stated that their health condition influences their willingness to accept an invitation for a test or screening: 'Explanation on how it is related to the health issues that I have' can be read alongside 'My current health condition' to infer that the reason for a test must be seen as relevant to the participants' individual experiences of health.

Knowledge of the test procedure also informs **comfort with the tests**, which, for some participants, is another way of responding to the emotional aspect of medical invitations. We were told by some participants that they would be unlikely to attend bowel tests and cervical screenings, for example, because of their discomfort or embarrassment with those tests. Emotional factors such as fear of results and anxiety about the procedure were also discussed and are expanded further in the following question on barriers to completing tests and screenings.

With a system as complex as the NHS, knowledge, comfort, and trust are mutually informative. As one participant stated, 'I am comfortable to take part, because I understand this system'. These factors can build on each other to create an environment of familiarity, participation, and mutual understanding. However, if they are not all maintained in communications and interactions, the participants indicate they would be less willing to accept invitations.

Some participants listed logistical factors such as **proximity and availability** as part of their decision-making process. Timing appointments around childcare and work commitments is vital for some participants. The location of the appointment is also important, as some participants stated they are less likely to accept invitations to sites that are far away or difficult to get to. It was suggested in the Cantonese-language group that reimbursement for travel costs would incentivise accepting invitations to tests and screenings.

Answers to Q9., *Are there any barriers for you to book or complete screenings or medical tests, like smear tests or bowel screening kits?*, were largely inverse to the previous question. One or two participants from each group said they faced no barriers. Those who did described barriers as a **lack of information about procedure, lack of information about purpose, difficulty booking and waiting, language barriers, embarrassment and discomfort, results anxiety, timing and transportation, and cultural and personal sensitivity**.

Similarly to the two parts of knowledge in deciding whether to accept an invitation, a **lack of clarity** about both the purpose of the test and the step-by-step procedure of the

test act as barriers to booking. Responses with these themes include 'Information on what is going to happen in the process of test/exam' and 'Lack of understanding/Not being clear on what the test is for or how it works'. One participant described that they did not understand the invitations that are sent out because of the language they are written in, and therefore did not engage with screenings, despite wanting to learn more.

For some participants who are willing to attend invitations, **difficulty booking an appointment** can act as a barrier. The process of trying to book a test was described as 'stressful and draining' as a result of delays and waiting times. Other participants discussed having to call multiple times and having to wait for an extended period to hear back from clinics, resulting in those participants abandoning the process. These issues were the most frequently cited barriers across the focus groups. **Language** was mentioned as a compounding issue, making understanding the invitation, booking an appointment over the phone, and engaging with NHS staff at appointments more complex, stressful, and time-intensive.

The Cantonese-, English-, and Farsi-language groups brought up **embarrassment and discomfort** as barriers to booking screenings and tests. One participant described fearing pap smears and ignoring the letters they had received about cervical screenings. As mentioned previously, bowel tests are another exam some participants would be less likely to attend due to embarrassment and discomfort. Where there is a chance for a screening to return a serious positive result, such as cancer, some participants stated **anxiety** of this potential acts as a barrier to booking the screening.

As with proximity and availability, logistical difficulties around **timing and transportation** were a barrier brought up in multiple groups. Participants described their lives busy with work, childcare, school, and other commitments, making finding time to schedule an appointment difficult, especially when time slots also have to accommodate an interpreter. Transportation was mentioned less frequently than timing and was not elaborated.

Finally, **personal and cultural sensitivities** were mentioned in the English- and Arabic-language groups as potential barriers to completing some tests. One participant answered that a lack of a guarantee for a same-gender clinician acts as a barrier for them. There was only limited discussion about specific cultural issues participants had faced. However, some members of the Arabic-language group discussed how some traditional medicines and practices for minor illnesses are not recognised by the NHS.

Communication and Engagement

The answers to Q10., *What would be the best way to share NHS information with you?*, fell mostly into eight categories: **email, letters, text messages, leaflets/flyers, social media, NHS webpage, phone calls, and in-person**. One participant gave a suggestion that did not fall into one of these categories; that being radio. **Email** was by

far the most frequent suggestion, occurring in discussion over twice as frequently as the next most common suggestion, **letters**.

There was some disagreement across and within groups about the most effective styles of communication. **Leaflets** were suggested in the Cantonese-, English-, and Polish-language groups, but it was mentioned in the Arabic-language group that flyers can be difficult to understand. Other issues with leaflets and letters were discussed in that group: because letters and flyers don't arrive translated, some participants used machine translation tools or asked others for help to understand the content. Some communications had also arrived late, meaning some participants lost appointment slots. It was suggested in the English-language group that written materials 'don't need to include everything—just the parts you want help with'. This way, potentially confusing auxiliary information would not get in the way of the core message being communicated. However, this should be considered alongside the role that information plays in shaping participants' decisions to attend invitations for screenings and tests.

Phone calls were also a contested point: while phone calls were suggested by some members of the Farsi-language group as a communication method, other members of that group and participants in other groups had described phone calls as a significant barrier to accessing NHS services. This is because interpretation is often not available during phone calls as initial points of contact between people and services. Long phone calls in which participants are expected to answer many questions without interpretation are not feasible for many of the participants.

One point that was brought up in several groups, especially regarding leaflets and **in-person meetings**, is the importance of meeting people **where they are**. Examples given include churches, community centres, schools, food banks, and workplaces. Participants in most groups expressed a desire to see NHS communications occur in spaces such as these, embedding the NHS into existing community networks and enabling better discussion and understanding. In-person meetings would also allow for questions to be answered and establish multilateral dialogue between communities and the NHS. These meetings should include interpretation where appropriate.

Finally, Q11., *What one thing or change would make it easier for you to use NHS services?*, resurfaced many themes that had been discussed during the sessions. The suggestions fell into the themes **shorter waiting times, easier to make appointments, better customer service, information about services and communication, local provision, and digital access**.

Shorter waiting times was the most frequent suggestion for making access to NHS services easier. Some participants proposed more specific changes, such as hiring more clinicians, more direct routes to specialist referral, and expanding existing services. However, there was broad desire for reducing time spent on waiting lists and

waiting for call-backs. Many comments on waiting lists were also connected to the theme of **easier to make appointments**. Making appointments ‘easier to understand, simpler to book and easier to access’ was suggested in five of the groups, indicating common dissatisfaction with the process of booking appointments.

One participant wrote that one difficulty with booking appointments with their GP was that ‘Reception can be a gatekeeper’. Negative experiences with NHS staff were also mentioned in two other groups, prompting desire for **better customer service**. Telephone staff were described in some instances as ‘unhelpful’ or ‘rude’, while one participant described an experience in which a clinician spoke to them dismissively and offered advice perceived as overly simplistic. Given other participants spoke of their positive interactions with individual staff members, this suggests inconsistencies in the quality of NHS Grampian experiences and the importance of individual interactions.

Information about services and communication included comments about the timeliness, clarity, and consistency of communications. Participants asked for ‘quicker initial guidance’ and ‘simple, consistent advice’ on where to turn when unsure about what service to use, indicating NHS 24 may not be seen as adequate for all participants, or that participants may not have been aware that guidance NHS 24 provides. One participant stated, ‘A lot of this information has been helpful but getting to everyone else’, while another asked for ‘Making information about NHS visible and accessible for all’. Participants in some groups noted that contacting 111 by phone was not feasible because a lengthy question-and-answer process without access to interpretation acts as a barrier to information. A lack of clear information in some cases can lead to significant financial costs: participants in the Farsi-language group discussed paying for private dental care because they were unsure what treatment was available through the NHS or what financial support they would have been eligible for.

Other participants asked for improved reminder and update communications for appointments, tests, and follow-ups, such as through text message or email. Participants in the Cantonese-language group mentioned that while they found being given leaflets during appointments helpful, recently they had been asked to print out leaflets themselves at home, which made them feel less supported. Documentation and administrative issues were also reported, with some participants in the Farsi-language group being asked to pay significant amounts of money for medical records, test results, and supporting letters, and in some cases not receiving the documents they had paid for with no clear indication of why not.

Participants in the Cantonese-, English-, Farsi-, and Polish-language groups highlighted a need for more **local provision** of services. For some, this meant ‘talks in the community’; for others, more ‘local and flexible services [including GP clinics]... closer to where people live’; and for others, it meant having transport services available to take people to appointments.

Digital access was also highlighted by a small number of participants as an area for improvement. Suggestions under this theme included easier ways to manage appointments and request prescriptions online and adding an AI chatbot to the NHS website to answer questions. However, given the unreliability of Large Language Models to provide factual advice, this type of tool in a medical context should be considered carefully and critically.

Challenges

The most significant challenge we faced was ineligible registrants making it difficult to gauge the progress of our recruitment or organise the focus groups and crowding out other potential participants. Although prior engagements we have run have had some ineligible or inauthentic registrants, none have been to this scale – almost 900 people signed up to the initial registration form. We responded to this by setting up a second layer of registration to filter out any bots and ensuring all facilitators were aware of the potential for ineligible participants. This issue was also communicated with NHS Grampian. We are currently reviewing our process for hosting and facilitating online engagement events in response to this new set of risks and assumptions.

Some focus groups were particularly affected by ineligible participants: the Bengali, Lithuanian, and first Farsi language groups had few legitimate participants, making the data from those groups difficult to analyse. The interpreters for those groups were invited to respond to the questions, drawing upon their significant experience supporting people through NHS appointments. The Polish and Russian language groups also had a few ineligible participants, but enough legitimate participants to run a successful group. The English, Arabic, and Cantonese language groups were very successful, with few or no ineligible participants. Additional in-person sessions were held with Farsi and Polish speakers to supplement the data from those groups. The online platform may have incentivised ineligible registrants to sign up, as they would not have to show up in person.

Online focus groups are typically more difficult to facilitate than in-person discussions. The lack of in-person contact can make some participants less engaged. This was exacerbated by the number of ineligible participants who joined the meeting but did not contribute to the discussion. The facilitators were aware of the risk of ineligible participants and were therefore conscious of encouraging communication through voice and text and removing ineligible participants as quickly as possible in order to make sure eligible participants felt comfortable to voice their perspectives.

It is thought that a small number of participants answered some questions by prompting generative AI rather than responding with their own experience. These participants may have felt the need to give the “right” answer, rather than describe their

own experience. This concern would have been easier to address in an in-person setting. Furthermore, in online settings, it can be difficult or impossible to observe the group dynamics and mood that inform much of the potential for focus group research.

Conclusion

People from the ethnic minority communities targeted in this series of focus groups have a good understanding of the NHS as a system they can turn to for health issues. However, beyond basic issues, there is uncertainty around the best point of contact for complex conditions, specialist services, and support with understanding NHS communications. There is desire for information about NHS Grampian services to be disseminated across a range of media, but it is important that information is communicated in a culturally sensitive manner, and ideally translated. Communication should also happen where people are, in cultural and community spaces, as well as to individuals directly. NHS 24 and 111 are important services, but language barriers and other issues cause some people to look for health information from personal networks, trusted professionals, web searches, and large language models.

Some participants were eager to be kept informed about the use of these focus groups to inform decisions and changes within NHS Grampian. In order to limit participants feeling their stories were extracted, it is important that follow-up be provided, such as through a “You Said, We Did” session or distribution of resources developed from this report.