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Community Languages, Translation and Interpreting Services

The development of the Community Languages Translation and Interpreting Improvement framework was commissioned by the Healthcare Inequalities Improvement team, NHS England and completed by South Central West Commissioning Support Unit, who funded the research undertaken by National Voices.

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List of abbreviations

AIS – Accessible Information Standard

BSL – British Sign Language

CSU – Community support unit

LEP – Low English proficiency

VCSE – Voluntary, community, and social enterprise

Executive summary

At the centre of the NHS Constitution is the promise that it “provides a comprehensive service, available to all” irrespective of their personal circumstances or identity. It also has a “wider social duty to promote equality through the services it provides”. The work that NHS England is undertaking within the translation and interpreting space is central to this promise as it looks to tackle entrenched but basic barriers to accessing health and care.

It is well-known that access to translation and interpreting is often piecemeal and patchy leaving people for whom English isn’t their first language unable to meaningfully engage in their diagnosis, treatment and self-management.

Our in-depth work with six marginalised communities across England showed to us that too often this results in lengthy delays in receiving the care they need or in some cases treatment taking place without consent in place. It is no surprise therefore that one participant told us, “It’s just good or bad luck” as to whether they would be offered access to an interpreter.

As a result, the sector is overly reliant on family members, often children, to translate for patients, with neither the health professional nor the patient expecting much better.

Our recommendations centre on professionalising the translation services offered, and reconsidering how AI and bilingual staff can be best used to support patients. It also makes clear that offering translated personal records and letters, alongside choice when using interpretation services, is essential in allowing people to have agency over their own health.

However, we must also confront the uncomfortable reality that many people feel racially discriminated against when they do not speak English well, and this, alongside unreliable and unprofessional experiences of interpreters, leaves them with little trust in the system.

Alongside working with the VCSE sector to help people better understand their rights to services, the NHS must be willing to engage with it to help win over peoples’ trust in proposed translation and interpreting service improvements.

But the benefits to be had will be worth the efforts needed to transform these services. It will result in patients feeling able to advocate for themselves, communities that feel included and patients who are supported to better look after themselves and their families.

We are grateful to the National Healthcare Inequalities Improvement Programme, NHS England, for commissioning this work and providing the opportunity for progress to be made in this space. NHSE's vision on health inequalities, 'Exceptional quality healthcare for all, ensuring equitable access, excellent experience and optimal outcomes' sets the foundation for such work. This project speaks to all three dimensions of that vision; in particular, equitable access to high quality care.



Jacob Lant
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Methodology

Overview

The Community Languages, Translation and Interpreting (CLTI) project, being undertaken by the National Healthcare Inequalities Improvement Programme at NHS England, intends to improve the provision of community language interpretation and translation services in NHS settings. This means improving people's ability to access an interpreter when seeing health professionals, whatever format or setting, or being able to read translated letters and pamphlets in a language other than English.

Recognising that lots of positive work has already happened in this area, we sought to build on previous work and recommendations in this space. We internally conducted a thematic analysis of reports from across National Voices' member and partner organisations, using external academic papers and other publications to support insights. To supplement the thematic analysis, we also convened a number of one-to-one conversations with relevant organisations to uncover granular insights and better understand the context of community languages, translation and interpreting services. These organisations included Birthrights, Prostate Cancer UK, NIHR, Race Equality Foundation, and the Royal College of Obstetricians and Gynaecologists.

We then conducted six focus groups across England, taking place both in-person and virtually as per participants' preference, to hear about people's experiences of translation and interpreting in NHS settings. We also used these sessions to co-design and test potential interventions or approaches which could drive real life improvements for people reliant on these services.

Approach

We reached out to six VCSE organisations, through our links into wider networks, who could act as trusted intermediaries into the range of communities we wanted to include in this work (as described below). We worked with the six organisations to provide us with community-specific insights, strategic advice where appropriate, and to co-ordinate a focus group of diverse and inclusive voices with people from their community. It was vital to work with such intermediaries as smaller, grassroots organisations who work closely with specific community groups will most often hold trusted relationships with individuals, allowing for more vulnerable and in-depth conversations.

Whilst remaining conscious of the importance of creating a safe space for people to share their experiences, both positive and negative, we also used the time spent together in focus groups to develop potential solutions to

improve people's experiences of translation and interpreting services. This ensured that we were not just generating intelligence on what the problems are, but also co-producing possible solutions with the people who use these services most often.

Once all focus groups were conducted, we ensured the six VCSE organisations had an opportunity to review that the insights gathered were accurately reflected, and to shape the final report and recommendations to ensure they are culturally and linguistically appropriate.

Community inclusion

Following our initial recommendations and in-depth discussion with NHS South Central West Commissioning Support Unit (NHS SCW CSU), we chose to reach out to the following communities:

- Bengali and Sylheti, based in East London (supported by Bangladeshi Mental Health Forum¹)
 - According to the 2011 Census Bengali/Sylheti² are one of the community groups, whose main language is not English, with the lowest prevalence of proficiency in English. Asian Bangladeshis form one of the UK's largest group of people of overseas descents and are also one of the country's youngest and fastest growing communities. They are a predominantly Muslim community which ensures we extend the diversity of background and cultures we engage with through this project.
- Mirpuri/Urdu, based in West Bromwich (supported by The Delicate Mind³)
 - According to the 2021 Census, Urdu is the fourth most commonly spoken language in the United Kingdom⁴. In addition to Urdu, individuals from the Pakistani community may also speak regional languages or other dialects, such as Pahari-

¹ Bangladeshi Mental Health Forum. (n.d.) Available at: <https://bangladeshimentalhealth.org/>. (Accessed: 23 October 2024).

² Office for National Statistics. (2011). *2011 Census: Detailed analysis – English language proficiency in England and Wales, Main language and general health characteristics*, Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/articles/detailedanalysisenglishlanguageproficiencyinenglandandwales/2013-08-30>. (Accessed: 23 October 2024).

³ The Delicate Mind. (n.d.). Available at: <https://www.thedelicatemind.org.uk/>. (Accessed: 23 October 2024).

⁴ Office for National Statistics. (2021). *Language, England and Wales: Census 2021*. Available at: [https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/bulletins/languageenglandandwales/census2021#:~:text=Panjabi%20and%20Urdu%20as%20main,\(4.3%25%2C%207%2C000\)](https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/bulletins/languageenglandandwales/census2021#:~:text=Panjabi%20and%20Urdu%20as%20main,(4.3%25%2C%207%2C000)). (Accessed: 23 October 2024).

Pothwari (including Mirpuri, an oral language widely spoken but rarely written) and Pashto. The 2011 Census states that Pakistani Punjabi (with Mirpuri and Pothwari dialects) had the second lowest prevalence of proficiency in English as a second language⁵.

- People seeking asylum, based in Greater Manchester (supported by Afrocats⁶)
 - We chose to facilitate one focus group for people who have arrived in England in more recent years, and focused on people seeking asylum as we know they face significant barriers and challenges in accessing health and care services. We recognise the significant diversity within this vulnerable group, who often have complex health needs and experience worse clinical outcomes⁷. The 2024 MBRRACE report also highlighted that individuals seeking asylum also interact with and experience great differences regarding maternity services, when compared to those born in the UK⁸.
- Polish, based in Bristol (Supported by Opoka⁹)
 - According to the 2021 Census, Polish¹⁰ remained the most common non-British nationality of individuals living in Britain. Speaking to the Polish community also presented the opportunity to capture the impact of translation services for those who live in more rural areas and are often in low-paid or casual labour such as agriculture. A National Farmers' Union 2017 survey¹¹ found that one third (32%) of the UK's seasonal

⁵ Office for National Statistics. (2011). 2011 Census: Detailed analysis – English language proficiency in England and Wales, Main language and general health characteristics. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/articles/detailedanalysisenglishlanguageproficiencyinenglandandwales/2013-08-30>. (Accessed: 23 October 2024).

⁶ Afrocats. (n.d.). Available at: <https://www.afrocats.org.uk/>. (Accessed: 23 October 2024)

⁷ Refugee Council. (2024). Helping refugees and asylum seekers to find healthcare. Available at: <https://www.refugeecouncil.org.uk/projects/helping-refugees-and-asylum-seekers-to-find-healthcare/>. (Accessed 23 October 2024).

⁸ MBRRACE-UK. (2024). Saving Lives, Improving Mothers' Care: Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2020-22. Available at: <https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2024/MBRRACE-UK%20Maternal%20MAIN%20Report%202024%20V1.0%20ONLINE.pdf> (Accessed 07 January 2025).

⁹ Opoka. (n.d.). Available at: <https://www.opoka.org.uk/>. (Accessed: 23 October 2024).

¹⁰ Office for National Statistics. (2021). *Language, England and Wales: Census 2021*. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/bulletins/languageenglandandwales/census2021>. (Accessed: 23 October 2024).

¹¹ Office for National Statistics. (2018). *Labour in the agriculture industry. UK*. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/internationalmi>

labour force were EU8 nationals (Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovenia and Slovakia). This ensures we have provided an opportunity for those facing the greatest socio-economic challenges to participate in this project and share their specific experiences.

- Roma, based in East London (supported by Roma Support Group¹²)
 - We chose to facilitate a focus group for Romani/Romanes individuals as the Romani/Romanes community are more likely to speak primarily spoken languages. Our previous work with this community demonstrates that they often face some of the most significant health inequalities facing any ethnicity group, and it has been recognised that the Roma community has a life expectancy up to 10 years less than non-Roma communities in the UK¹³.
- Somali, based in North London (supported by Caribbean & African Health Network¹⁴, in partnership with Phoenix Family Service Community Pantry¹⁵)
 - The UK has the largest Somali community in Europe, with many Somalis living in England. According to the 2021 Census, those who identified as Somali had a younger age profile than the general population of England and Wales, with 48% being aged under 21 years¹⁶. This ensures we have a scope of ages participating in focus groups.

All groups were held face to face, bar the Polish and Mirpuri/Urdu which were held online at the request of the local VCSE organisations we were working with.

[gration/articles/labourintheagricultureindustry/2018-02-06?source=your_stories_page](https://www.gov.uk/government/articles/labourintheagricultureindustry/2018-02-06?source=your_stories_page). (Accessed: 23 October 2024).

¹² Roma Support Group. (n.d.). Available at: <https://www.romasupportgroup.org.uk/>. (Accessed: 23 October 2024).

¹³ Gov.uk. (2022). Improving Roma health: a guide for health and care professionals. Available at: <https://www.gov.uk/guidance/improving-roma-health-a-guide-for-health-and-care-professionals#:~:text=Roma%20communities%20experience%20social%20exclusion,under%20the%20Equality%20Act%202010>. (Accessed: 23 October 2024).

¹⁴ Caribbean & African Health Network. (n.d.). Available at: <https://www.cahn.org.uk/>. (Accessed: 23 October 2024).

¹⁵ Phoenix Family Support Services. (2024). Available at: <https://enfielddirectory4all.co.uk/families-communities/grassroots-pantries/>. (Accessed 23 October 2024).

¹⁶ Office for National Statistics. (2023), *Somali populations, England and Wales: Census 2021, Somali populations, England and Wales*. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/somali-populationsenglandandwales/census2021> (Accessed: 23 October 2024).

Limitations

Although communities for inclusion were decided upon through research and analysis, alongside thorough conversations with NHS SCW, we recognise the limitations that come with only speaking to a limited number of community groups within a specific geographical scope. There will be many other community and language groups who also experience challenges with language and translation services whose specific experiences and insights are not reflected in this report.

We also recognise that British Sign Language (BSL) has not been included in the project at the request of NHS SCW CSU. We understand that some of the challenges faced by D/deaf individuals who use BSL have been explored to a greater extent by the ongoing work on the Accessible Information Standard (AIS)¹⁷.

¹⁷ NHS England. (2017). Accessible Information Standard. Available at: <https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/>. (Accessed: 23 October 2024).

Overarching themes

Analysis of experiences shared during the focus groups determined several overarching themes, with experiences resonating across several communities we spoke to. These themes are as follows:

1. Accessibility

- Options to access appointments and health care information in alternative, more accessible formats
- Availability of translated materials
- Increased waiting times and translator cancellations
- Need for extended appointment length

2. Digital challenges

- NHS App
- Online forms
- Telephone or video consultations
- Misinterpretation using AI

3. Advocacy and rights

- Right to translation
- Patient safety
- Shared decision making and informed consent
- Continuity of care
- Litigation

4. Discrimination and racism

- Judgement and stigma around low English proficiency
- Cultural understanding and discrimination, including gender appropriateness and differences in dialect
- Intersectional discrimination
- Wellbeing

5. Quality of translators and interpreters

- Misinterpretation and mistranslation
- Inappropriate behaviour and training of translators
- Privacy concerns

6. Carers

Throughout the themes we have included more specific community concerns shared by focus groups by presenting them in coloured boxes. The key is as follows:

Bengali/Sylheti
Mirpuri/Urdu
People seeking asylum
Polish
Roma
Somali

Accessibility

NHSE's health inequalities vision outlines the ambition for 'Exceptional quality healthcare for all through equitable access, excellent experience and optimal outcomes'. Our findings on accessibility affected all six focus groups and was often the most vocal concern raised in the groups, with translation and interpreting barriers preventing people from even starting on the journey to receive the health care they needed. It is therefore reassuring that this is highlighted in NHSE's health inequalities vision.

"I find it difficult to get past receptionists who can sometimes be rude or unhelpful, especially if someone is clearly struggling to communicate."

- Bengali/Sylheti focus group participant

Options to access appointments and health care information in alternative, more accessible formats

NHS England's [Guidance for commissioners: Interpreting and Translation Services in Primary Care](#), states that "On registration with a primary care service [...] patients requiring language support should be made aware of the different types of interpreting available to them"¹⁸. However, participants from all focus groups shared the challenges they face when seeking access to primary care (e.g., making an appointment), as translation and interpreting are not offered at this stage. Equally, if they receive a letter or text message asking them to contact their GP, they are unable to understand the options to do so due to the being primarily in English, as are the access routes offered (e.g., e-consult form, telephone, and face to face). The latter is worsened for those who have low English proficiency (LEP).

¹⁸ NHS England. (2018). *Guidance for commissioners: Interpreting and Translation Services in Primary Care*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2018/09/guidance-for-commissioners-interpreting-and-translation-services-in-primary-care.pdf>

"It would help to have our letters in Somali but no one does it, the system isn't available."

- Somali focus group participant

"Roma Support Group is how access happens."

- Roma focus group participant

"AI has a role, but if letters are generated by AI, there could be inaccuracies/slight misunderstanding, need to either disclose it is AI, or get humans to check."

- Polish focus group participant

An individual in the Roma focus group reported missing a surgery appointment in 2022 as the appointment letter was not translated. This case highlights several systemic issues, such as a lack of translated written communications for important medical appointments, difficulty in understanding instructions or notes from healthcare providers, challenges in arranging appointments due to language barriers, and potential health risks due to missed or delayed treatments. The patient also mentioned that their GP writes things down for the patient, but these notes are not understood.

"There is no understanding between myself and the doctor. If there is no translator there, and the doctor gives me a note, I don't understand where I need to go and I might miss the appointment."

- Roma focus group participant

Individuals in the Roma focus group also noted that the NHS App is not usable for those who cannot read or write. Research has found that at the end of Key Stage 2 just 23% of all Gypsy/Roma pupils in England achieved Level 4 or above in reading, writing and mathematics. This compares with 75% of all pupils nationally¹⁹.

Several participants from the Bengali/Sylheti focus group and people seeking asylum focus group, also shared that they tend to use body language and actions to help communicate and emphasise what they are saying. However, when they are using a telephone interpreter, they can't use

¹⁹ Ofsted. (2014). Overcoming barriers: ensuring that Roma children are fully engaged and achieving in education. Available at: https://assets.publishing.service.gov.uk/media/5a80e6caed915d74e6231178/Overcoming_barriers_-_ensuring_that_Roma_children_are_fully_engaged_and_achieving_in_education.pdf. (Accessed: 25 October 2024).

their body language and actions so they struggle to properly explain their needs to the receptionist or primary care professional.

Although there have been mixed experiences regarding accessibility of healthcare when needing translation services across all groups, we were told of positive cases where members of the community felt supported by healthcare services.

A participant from the Mirpuri/Urdu focus group noted that she received a text reminder for her vaccination in Urdu without needing to sign up for this type of communication, suggesting the GP had arranged this for her automatically. This was particularly helpful as she, like many in the community, is confident in speaking English but finds reading and writing much more difficult, so these translated written communications were very effective.

"I didn't sign up for communications in Urdu so someone at the GP must have flagged that I spoke another language."

- Mirpuri/Urdu focus group participant

The example of the above participant receiving a text reminder in her chosen language demonstrates that it is possible to record and flag people's access and communication needs. Yet from our findings it appears seldom achieved across the NHS.

Availability of translated materials

Another common theme that arose across many focus groups, was the availability of health information in languages other than English. Some participants shared examples where they received an information leaflet in another language once they had been diagnosed with a medical condition. While this was considered useful and appreciated by participants, many highlighted the need for preventative health information to be more widely available for non-English speakers. People in the Bengali/Sylheti focus group, Mirpuri/Urdu focus group, and people seeking asylum focus group particularly highlighted the need for wider health information to be translated, not just information about conditions more prevalent in those community groups (e.g., diabetes, hypertension etc).

The Mirpuri/Urdu focus group shared that they have never seen any materials to help them better manage disabilities, including deafness, blindness, and autism. In the Mirpuri/Urdu focus group, a participant flagged this as a concern as she is a carer and interprets for her autistic son but has not had access to any translated resources for additional support or learning.

It is important to note that translated written materials are not a "one size fits all" approach. Some dialects and languages can be primarily spoken

languages, and it is also important to consider low literacy in native languages. Therefore, providing translated health information in alternative formats (such as video or audio) was considered an important factor, particularly in the Bengali/Sylheti, Mirpuri/Urdu and Romanes focus groups.

Our thematic analysis showed that medical professionals and patients were highly satisfied with MediBabble²⁰. Such a programme could be used to initially translate resources and tailored communication, although this should be reviewed by a qualified translator to determine accuracy.

Increased waiting times and translator cancellations

A number of participants across the six focus groups shared that they feel they regularly wait longer than average to access an appointment with a translator present. Participants noted that they must request an interpreter with a minimum of one week notice yet are sometimes still denied access to one. This meant that they were more likely to have to rely on family members to translate for them, especially if the matter needs immediate attention.

"I asked [for a translator], I was told my procedure should be delayed until interpreter available. However, my notes recorded that I need an interpreter. In the end the wait is longer and I am still waiting. I don't fully understand what the procedure will involve – so I can either keep waiting or undertake it uninformed."

- Polish focus group participant

"It's very difficult because we don't know English. Healthcare professionals talk very fast. I have asked for a translator but I wasn't given one"

- Roma focus group participant

"Even 2 weeks ago I had an appointment and they said, "find your own translator" - I didn't know where to find one."

- Roma focus group participant

²⁰ Al Shamsi, H., Almutairi, A. G., Al Mashrafi, S., & Al Kalbani, T. (2020). 'Implications of Language Barriers for Healthcare: A Systematic Review', *Oman Medical Journal*, 35(2), e122.
<https://doi.org/10.5001/omj.2020.40>

One participant in the Bengali/Sylheti focus group shared that she has waited 1-2 months for a GP appointment in order to have a translator present, all whilst her condition was deteriorating.

Participants also shared circumstances in which they attended an appointment only for a translator to not be present, despite their repeated requests and assurance from staff that one would be organised. This resulted in them being forced to restart the appointment booking process over again, effectively putting them at the back of the queue again.

"I asked for a translator, I didn't get a translator, I missed the appointment."

- Roma focus group participant

"If I have a translator they come late and you have to go in [to see the GP] before [the translator arrives]."

- Somali focus group participant

"I've asked for more investigations [on causes of symptoms] but ten times told to take paracetamol, there was no translator on hand and I got to the stage where my health issue deteriorated."

- Somali focus group participant

People at greatest risk of experiencing health inequalities, and people who have LEP, may be deterred to attend a second appointment if the first appointment did not go ahead due to a translator cancelling or the appointment failing to work due to a translator not being present. This is because they are more likely to work zero-hour contracts and/or have precarious and inflexible work environments, meaning it can often be harder to take time off for health appointments and they may also be at greater risk of financial hardship by doing so. The cost of transport to/from appointments can also be significant. These individuals also often have greater caring responsibilities which means they will need to organise alternative care if they need to attend appointments.

Similarly, poor translation and interpreting services are also detrimental to wider NHS service utilisation. For example, there is a recognised increase in the use of A&E due to poor access to the GP for those in need of interpretation and translation services. There is equally a loss of productivity due to cancelled appointments, and individuals are more likely to 'did not attend' (DNA). Each of these factors contributes to increasing the electives backlog.

Need for extended appointment length

The average GP appointment is approximately 10 minutes long. However, this allows for little real conversation between a clinician and patient when each party requires translation to communicate. We already know people may take longer to open up about sensitive and difficult health concerns, but this is exacerbated when someone is also having to build a rapport with their translator, understand the mechanism of translation, and become comfortable about sharing their concerns with a third party as well as the doctor. It is therefore understandable that participants shared that they rarely receive enough time in appointments to fully express their concerns. Not only does this lead to insufficient care and understanding, but also leads to patient safety risks if a problem is not thoroughly understood by a clinician. At worse, such risks may lead to patient deaths, as highlighted by the Health Safety Investigation Branch report²¹.

A participant from the Somali focus group noted that although they feel safe with the doctors, a ten minutes appointment is just not long enough to allow for translation. They flagged that if an interpreter is needed, whether provided by a family or professional, 20 minutes (two slots) is needed to allow time for translation.

2. Digital challenges

Throughout all focus groups, concerns around digital access and service provision came up repeatedly. Due to the overarching nature of digital challenges, and significant overlap with other themes, we have chosen to explore these insights further in the following section. Specific communications challenges experienced by particular groups have been explored further in National Voices' [Accessible and inclusive communication within primary care: What matters to people with diverse communication needs report](#).

We are aware that one of NHSE's 5 strategic priorities for tackling health inequalities is 'Mitigate Against Digital Exclusion', and recognise the domains for action outlined in [NHSE's Inclusive digital healthcare framework](#), which act as drivers to tackle digital exclusion. However, at the time of writing, both the NHS app and online forms remain inaccessible to large numbers of the population. As of 2024, 2.6m households struggle to afford a mobile, 1.9m households struggle to afford broadband, and 8.5m adults

²¹ Hill, M. (2023), *NHS interpreting service problems contributed to patient deaths*, BBC News. Available at: <https://www.bbc.co.uk/news/uk-england-bristol-66605536#:~:text=The%20Fol%20found%20that%20of,to%20death%20or%20brain%20injury> (Accessed: 25 October 2024).

(16% of the UK population) lack essential digital skills²². In 2021, The University of Oxford Migration Observatory found that 50% of those who could not speak English well or at all are unemployed and are therefore more likely to be experiencing socio-economic inequality²³. Consequently, these individuals are also more likely to experience digital exclusion.

"E-consults and online access is completely inappropriate as some won't have broadband and most don't understand why they need to complete the form or how to."

- Bengali/Sylheti focus group participant

NHS app

There are a number of concerns around the accessibility of the NHS app. The three greatest barriers heard from our focus groups were from those with limited English, no and low-literacy levels, and digital exclusion.

The NHS app is currently only available in English. Therefore, signposting to the app for individuals who have low-English proficiency (LEP) is inappropriate and ineffectual. As a result, all the people we spoke to in our focus groups are at a significant disadvantage to others who can use the app to book appointments, order prescriptions, access their health record, and access a number of other resources and features the app provides. In turn, this increases the workload for receptionists, front-of-house teams and medical professionals as individuals are forced to access these resources via telephone or face to face.

Several participants who are able to read and write from across focus groups also emphasised the potential benefits of having letters translated into their primary language. This would help them to understand their condition, health and care needs, and next steps.

A number of participants in the Roma focus group also highlighted that they only access the NHS app with support from Roma Support Group (RSG). Those who do not have access to organisations such as RSG may also face exclusion due to the challenges they face when seeking to access the NHS app. More broadly, research conducted by RSG found that only 2% of Roma

²² Good Things Foundation. (2024). Digital inclusion: What the main UK datasets tell us. Available at: [https://www.goodthingsfoundation.org/policy-and-research/research-and-evidence/research-2024/digital-inclusion-datasets#:~:text=What%20we%20know%20about%20digital%20inclusion:%20the%20headline%20statistics%20Back,device%20and%20home%20internet%20\(c570k\)](https://www.goodthingsfoundation.org/policy-and-research/research-and-evidence/research-2024/digital-inclusion-datasets#:~:text=What%20we%20know%20about%20digital%20inclusion:%20the%20headline%20statistics%20Back,device%20and%20home%20internet%20(c570k).). (Accessed: 25 October 2024).

²³ The Migration Observatory. (2024). English language use and proficiency of migrants in the UK. Available at: <https://migrationobservatory.ox.ac.uk/resources/briefings/english-language-use-and-proficiency-of-migrants-in-the-uk/#:~:text=English%20proficiency%20is%20widely%20regarded,to%20partake%20in%20language%20courses>. (Accessed: 25 October 2024).

use the NHS app, excluding 97% of an entire community from easily accessing care²⁴.

Lessons can be learnt from BSL 999, which allows the user to record a short video in BSL and request emergency assistance²⁵. A participant in the Mirpuri/Urdu focus group shared that their son has used this on multiple occasions – once for himself and another time to help a stranger who was injured on the street – and had successfully accessed help on both occasions. Such resources encourage confidence in accessing health services more widely, but digital exclusion must be accounted for in these circumstances.

In relation to the BSL 999 case study – “What if he was really hurt or had an accident, who would help him? I worry when we’re not with him.”

- Mirpuri/Urdu focus group participant

Online forms

To a similar extent, online forms are also rarely accessible to individuals who face digital exclusion. Across the NHS, online forms can be used for a variety of reasons, such as:

- Contacting your GP surgery, including to complete e-consult forms for ill health, ordering repeat medication, or administrative requests
- Registering with a GP and updating contact details/clinical records
- Requesting online access to medical information

Many focus group participants, across the range of languages, mentioned that they are deterred from using online forms because they can often be lengthy, time-consuming, unavailable in languages other than English, use technical or specialist language, and they often feel they don’t know how to express their care needs in writing. Many participants noted that if online forms were available in a range of languages, they would be more likely to access using this method.

Participants in the Bengali/Sylheti group noted that they have to ask family members or friends for help to complete a GP e-consult form, but the online

²⁴ Roma Support Group. (2024). Enablers of digital inclusion in primary care for Gypsy, Roma and Traveller Communities. Available at: https://www.romasupportgroup.org.uk/uploads/9/3/6/8/93687016/enablers_to_digital_inclusion_in_primary_care_for_gypsy_roma_and_traveller_communities_final..pdf. (Accessed 25 October 2024).

²⁵ 999 BSL. (n.d.). Available at: <https://999bsl.co.uk/>. (Accessed: 25 October 2024).

service is closed in the evening by the time their family member or friend returns from work and can help.

Participants in the Mirpuri/Urdu focus group noted that online forms, especially e-consult forms, do not have any questions relating to a person's access or communication needs. Therefore, people are unable to request interpreters or highlight their specific needs, resulting in inaccessible call-backs or text message replies from the GP in English. This would also be inaccessible for people who are deaf or have low English literacy.

One female participant in the Bengali/Sylheti group was experiencing gynaecological problems and wasn't comfortable asking for help to complete the e-consult form, but when she visited the GP reception directly to ask for help, she was turned away due to her LEP. She ended up waiting two months to see a healthcare professional, throughout which her condition worsened, and she was left in pain and discomfort.

Telephone or video consultations

Another element of digital exclusion that arose during the focus groups, were digital challenges specific to telephone or video consultations. We know that many communities with lower English literacy are also more likely to be in more precarious work (e.g., Zero-hour contracts or inflexible employers), and/or face greater social inequalities and so may not be able to afford the use of digital technology (including devices, mobile data and/or broadband).

One participant in the Urdu focus group, who cared for her two sons with specific care needs (one of whom is deaf and the other is autistic), highlighted the difficulty of navigating digital services and video consultations from her "small phone screen". Other participants shared difficulties in accessing telephone appointments as they were unable to speak to the interpreter and medical professional face to face, thus felt less able to build trust to feel like they could openly share their health concerns.

"I used Google translate for medical terms and to get written advice in both English and Polish, and then I compare and select what fits. But I just looked at 111 website and it says call if I need interpreter. How would you understand or carry that out if you have no English at all?"

- Polish focus group participant

On occasions where they were asked to take photos of their symptoms (e.g., rash, eye problems etc) and submit them to the GP via a text message link, we heard about issues with not having enough mobile data, issues with broken phone cameras, and a lack of technical skills to complete the

request. In turn, this left people feeling frustrated, as though they were not taken seriously, and in some cases, people being misdiagnosed and prescribed the wrong medication.

Since COVID, some GPs tend to only offer appointments online or over the phone, and participants feel that online options are very generalised with limited options or ability to communicate their pain or other symptoms. Participants from the Somali group noted that they have to ask their children to write the online form for them, but often have to wait for their children to return from school/college to do so, and by then the online form process has been closed overnight.

Another example of exclusion in digital telephony was in relation to the offer for translators. One participant from the Bengali/Sylheti focus group shared an example of when she needed to call 111 to request medical assistance for her husband who had fainted and fallen in the bathroom. However, she was not aware of the option for a Bengali/Sylheti interpreter as the option was presented to her in English. Therefore, she struggled to navigate the call and described feeling distressed and helpless because she was unable to fully articulate the problem to medical professionals. This resulted in the medical professionals guessing what was wrong rather than providing options and listening. As a result, it took “a few hours” before the couple received appropriate care, during which her husband experienced another fainting episode.

Misinterpretation using AI

Very few participants had used Artificial Intelligence (AI) tools, such as Google Translate, during a healthcare appointment. Some participants shared that they had used AI to translate materials, such as letters and resources, but they feel the translation is often incorrect or does not make sense.

“When pregnant four years ago I had to use Google Translate at an antenatal appointment. Healthcare worker just used this and didn’t ask if I wanted a live translator or if I gave consent [to Google Translate being used].”

- Polish focus group participant

This is unfortunately unsurprising, as Google Translate has been found to have higher translation accuracy levels when translating from English to another Western language. For example, English to Spanish translations

have been found to be 94% accurate²⁶. In contrast, Middle Eastern languages such as Farsi and Armenian have an accuracy level of 67.5% and 55% respectively²⁷. Arguably, AI translation rarely accounts for the differences in regional dialects or spoken dialects, adding to the inaccuracy of AI translation experienced for these groups.

"Google Translate works for more Western languages but the further east or south you go globally the more spoken dialects emerge - which cannot be translated accurately using existing technology."

- Mirpuri/Urdu focus group participant

A participant in the Polish focus group shared understanding of an AI system that was being rolled out in a handful of areas. The Magic Notes AI tool writes summaries and suggests follow-up actions for clinicians. The app also drafts letters, and participants suggested it may be able to do so in alternative languages to English²⁸.

Due to the misinterpretation that often occurs when using AI, it is understandable that when one participant tried to use Google Translate in an appointment, the present clinician refused to look at the translation. Several participants across focus groups shared concerns regarding the inability to truly consent to treatment or care if they do not understand the choices they are presented with and the suggested course of care.

Arguably, without substantial safeguards, the use of AI in healthcare translation could cause or amplify serious harms to people and communities, with those speaking a language with poorer AI translation accuracy more likely to experience further widening of health inequalities²⁹.

²⁶ Phrase. (2023). Research vs Practice: How Accurate Is Google Translate?. Available at: <https://phrase.com/blog/posts/is-google-translate-accurate/>. (Accessed: 25 October 2024).

²⁷ Taira, B. R., Kreger, V., Orue, A., & Diamond, L. C. (2021), 'A Pragmatic Assessment of Google Translate for Emergency Department Instructions', *Journal of general internal medicine*, 36(11), 3361–3365. <https://doi.org/10.1007/s11606-021-06666-z>

²⁸ The Guardian. (2024). Social workers in England begin using AI system to assist their work. Available at: <https://www.theguardian.com/society/2024/sep/28/social-workers-england-ai-system-magic-notes>. (Accessed 25 October 2024).

²⁹ The Health Foundation. (2024). Priorities for an AI in health care strategy. Available at: <https://www.health.org.uk/publications/long-reads/priorities-for-an-ai-in-health-care-strategy>. (Accessed: 25 October 2024).

3. Advocacy and rights

Right to translation

In line with the Equality Act 2010, it is a legal right for individuals with LEP to have access to a translator when using health and care services³⁰. The Health and Care Act 2022 and public sector equality duty also emphasise this requirement. This makes sure that patients are provided with the right care, with informed consent (which we explore further below). Nonetheless, a number of participants shared inconsistencies in assignment of a translator, and perceived eligibility to access one.

Participants also shared that whilst for some appointments they were assigned a translator, for others they were not, and did not understand why this was. Our focus group work highlighted that the issue of raising awareness of the rights to interpretation and translation remains pertinent, as well as the need to ensure that these legal rights are upheld.

"I know that having a translator was a legal right, but I have had to push for translators at my GP."

- People seeking asylum focus group

"Even when we do say we have the right to see someone, the translator is not offered."

- Somali focus group participant

All participants in the people seeking asylum focus group knew that having a translator was a legal right. However, they shared that they regularly have had to advocate for themselves and push for access to a translator at their GP.

In the Somali focus group, one woman flagged that she was unaware that she had a right to a translator and had only learnt this from the focus group session. Other women shared that they knew they had a right to a translator, but it made no difference as reception informed them that there were no translators available.

³⁰ NHS Shared Business Services. (2021).

Interpretation and Translation Services. Available at:

<https://www.sbs.nhs.uk/services/framework-agreements/interpretation-and-translation-services/>. (Accessed: 25 October 2024).

Patient safety

Guidance for commissioners: Interpreting and Translation Services in Primary Care, states that “the use of anyone under the age of 16 for interpretation is not acceptable in any circumstance other than when immediate and necessary treatment is required”³¹. However, multiple focus group participants, from across all six focus groups, shared instances of children translating on their behalf.

“When I take my son with me, she [the receptionist] talks to my son so nicely and ignores that I am there. People who speak English automatically get treated better.”

- Bengali/Sylheti focus group participant

In the Polish focus group, it was shared that an elderly patient had relied on their 10-year-old grandchild to translate for them during diagnostic scans. Throughout the process, nurses had to hide visual procedures from the child to ensure he was not scared whilst he translated for his grandmother.

Other participants who tend to rely on their children also shared that it can sometimes be uncomfortable for the child and parent when the child is translating, especially concerning sensitive or private concerns (such as gynaecological and urological matters, or symptoms of more life-threatening conditions such as cancer). This concern is especially prevalent for communities and groups with stronger cultural nuances or religious beliefs.

Participants also shared the difficulty they have booking appointments due to their children being in school when appointments are available or e-consult forms are open, emphasising the importance of enhanced access such as offering evening and weekend appointments). We heard in our focus groups that professionals often expected a family member to be able to translate and that patients also presumed a translator would not be made available. This dual reliance on family members, most often children, highlights the scale of the issue and the pressure placed on children, some often under 18 years of age. It also shows how little trust there is in the system to provide a professional interpreter.

“I’m very lucky that my husband can speak English. I felt pity for other Romanians [in hospital], results weren’t finished, they had no clue where to be.”

- Roma focus group participant

³¹ NHS England (2018). *Guidance for commissioners: Interpreting and Translation Services in Primary Care*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2018/09/guidance-for-commissioners-interpreting-and-translation-services-in-primary-care.pdf> (Accessed: 25 October 2024).

One participant in the Somali focus group shared that their child, who is asthmatic, was in hospital for three nights. She highlighted that healthcare staff undermined her and talked to her child instead, as her child has stronger English proficiency. The participant's LEP resulted in her communicating with staff using broken Somali to English translation on an app. She shared that she felt "useless" and was only able to stand there whilst healthcare staff made decisions regarding her daughter's care without engaging with her. The mother was therefore unable to consent to her daughter's care, which the focus group facilitator asked the translator to explain to the mother was illegal.

Circumstances of other family members translating on a patient's behalf were also widely experienced across all focus groups with some people having their children call via WhatsApp from abroad or asking hospital consultants to come back outside of ward round when their child would be available to translate via phone.

There was a strong consensus in the Somali focus group that they most often rely on a family member to translate rather than a professional interpreter, with many agreeing that they take their children with them to translate and advocate for them, as they have more trust in their child than in the translators provided by the NHS. At times, having their child present even improves how they are treated by the medical professionals, due to their child's stronger English proficiency. This exemplifies the need for trust to be built between patients, translators, and healthcare staff, to relieve the pressure on children to translate.

Shared decision making and informed consent

Interpretation provided by family members, friends, low-quality interpreters, and AI, is likely to be less accurate due to specific medical terminology.

NHS England state that "shared decision making and consent are fundamental to good medical practice", noting that "serious harm can result if patients are not listened to, or if they are not given the information they need, and time and support to understand it, so they can make informed decisions about their care"³². However, if a translation is inaccurate a patient is unable to truly understand their choices surrounding shared decision making or provide their informed consent to progress with a healthcare plan.

In reference to a translator mistranslating - "I'm saying this, he's saying that."

- People seeking asylum focus group participant

³² NHS England. (n.d.) Decision making and consent. (Accessed: 25 October 2024).

An individual in the Roma focus group shared that when you get a diagnosis or test results, you are given multiple options, and resultantly this offers up multiple risks. They said that if you don't have an interpreter, you don't understand this and may put yourself unknowingly at risk. They said they were concerned that people were consenting to care or treatment they didn't understand, and feared a patient may lose their life due to this misunderstanding.

One participant in the Urdu focus group emphasised that she was grateful to recently receive care, regardless of the hassle of trying to access and navigate the system without proper translation and interpreting. However, she shared that she does not know what diagnostic scans or treatment she received or why she had to have them.

Continuity of care

Guidance for commissioners: Interpreting and Translation Services in Primary Care, states that "Good practice indicates that where a patient requires continuity of care, systems are in place to enable them to access the same interpreter where this is practicable"³³. However, out of all the participants who had accessed a translator, only one shared that she had been assigned the same translator more than once.

When continuity of care is not offered through assignment of the same translator to patient, there is no opportunity to build trust with a translator or to develop a consistent translation and understanding of care and treatment, especially during ongoing periods of care for the same condition.

This may result in the need for further appointments to clarify a patient's concerns, and at worst could be extremely detrimental for diagnosis, inconsistencies in treatment, and serious harm.

"It would be good to see the [interpreter's] name in advance and see the same translator at our appointments."

- People seeking asylum focus group participant

A participant in the Mirpuri/Urdu focus group shared that his elderly mother relies on a translator but sometimes withholds discussing her symptoms as she is uncomfortable with being transparent with a stranger. He summarised that 'she needs that reassurance and feeling of security to be able to have

³³ NHS England. (2018), *Guidance for commissioners: Interpreting and Translation Services in Primary Care*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2018/09/guidance-for-commissioners-interpreting-and-translation-services-in-primary-care.pdf> (Accessed: 25 October 2024).

confidence in that interpreter', emphasising the need for a clear confidentiality agreement between the translator, doctor, and patient. Encouraging continuity of care by ensuring that the same interpreter is assigned to a patient each time they attend an appointment, would allow the patient and interpreter to build a relationship, mitigating the discomfort the patient feels due to discussing symptoms with a stranger.

"My elderly mother needs a translator as family members are not always available but sometimes [she] holds back her symptoms as she's not confident speaking with an interpreter because they're a stranger."

- Mirpuri/Urdu focus group participant

"She needs that reassurance and feeling of security to have confidence in that interpreter."

- Mirpuri/Urdu focus group participant

A participant in the Bengali/Sylheti focus group shared that their local GP surgery used to have two days allocated where a Bengali/Sylheti translator was available all day in clinic. Not only could people be confident they'd be able to access interpreters on that day, but where possible this also presented an opportunity for them to pre-plan their schedules to fit around this. The quality of care was also improved due to clearer communication and mutual understanding.

Litigation

Although no focus group participants shared instances of legal action which occurred because of poor translation, such cases have transpired more broadly across the NHS.

In 2023, the BBC submitted a Freedom of Information (FoI) request to the Healthcare Safety Investigation Branch (HSIB), regarding a review of all investigations which involved cases of babies dying or being diagnosed with a severe brain injury in the first seven days of life, occurring from 2018-2022. Of the 2,607 reviewed cases, 80 included references to interpretation or communication problems due to language difficulties (3.1%), which were considered to be a contributing factor to death or brain injury³⁴.

³⁴ Hill, M. (2023), *NHS interpreting service problems contributed to patient deaths*, BBC News. Available at: <https://www.bbc.co.uk/news/uk-england-bristol->

One such claim is Nilujan Rajatheepan v. Barking Havering and Redbridge University Hospitals NHS Trust. The case concerned a failure to ensure a Sri Lankan mother, who was also an individual seeking asylum with LEP, understood breast-feeding guidance³⁵. This led to her baby developing cerebral palsy. The parties' experts agreed that if the mother and the midwives were not able to communicate effectively with one another, the Defendant's had breached their Duty of Care to both mother and son, in failing to provide the care expected of the midwife and/ or NHS Trust. As a result of the ruling, the NHS had to pay millions of pounds in compensation³⁶. In a similar case, the NHS agreed a settlement totalling £13m³⁷. It may be helpful to consider translation and interpreting costs within the context of legal compensation when things go wrong due to poor communication.

"Lack of interpretation can lead to loss of health or life. Couple of days ago, a young person [used] an interpret on a 111 call. He had a cardiac arrest on the call, 111 handler had to give CPR instructions to family via interpreter, who panicked and hung up, ending call connection for all."

- Polish focus group participant

"When you get a diagnosis or test results, you are given multiple options, [so there are]

multiple risks. If you don't have an interpreter, you don't understand this and may put yourself at risk. People may consent to something they don't understand. You can lose your life as a result."

- Roma focus group participant

"My daughter was diagnosed with diabetes but before [diagnosis] every time I took her to the GP I was told she's just young but then

[66605536#:~:text=The%20of%20found%20that%20of,to%20death%20or%20brain%20injury](#) (Accessed: 25 October 2024).

³⁵ Cunningham, T. (2018). *Lost in Translation: The importance of ensuring that medical advice is understood by the patient*, Available at: <https://clinicalnegligence.blog/2018/04/27/lost-in-translation-the-importance-of-ensuring-that-medical-advice-is-understood-by-the-patient/> (Accessed: 25 October 2024).

³⁶ Dyer, C. (2018), 'NHS failed to communicate feeding advice to refugee mother, court rules', *The British Medical Journal*, Available at: <https://doi.org/10.1136/bmj.k1711> (Accessed: 25 October 2024).

³⁷ Dyer, C. (2021), 'NHS agrees to pay £13m for boy who was left brain damaged from lack of nutrition after birth', *The British Medical Journal*, Available at: <https://doi.org/10.1136/bmj.n371> (Accessed: 25 October 2024).

she fainted at school and was taken to hospital [and diagnosed]. It has affected her eyes and it was left [undiagnosed] for so long."

- Somali focus group participant

A man in the Roma focus group shared the experience of his wife, who was diagnosed with cancer after three years of experiencing symptoms, due to poor communication and accessibility requirements surrounding LEP. This case illustrates several critical issues, such as challenges effectively communicating symptoms due to language barriers, lack of consistent access to translators throughout the healthcare journey, and potential misunderstanding of test results and follow-up instructions. The man emphasised the need for translators to be available at every stage of the healthcare process, from making appointments to seeing the doctor. This case underscores the potential life-threatening consequences of inadequate translation services in healthcare settings, and the serious harm that may occur from poor communication.

4. Discrimination and Racism

Judgement and stigma around low English proficiency

Participants across all six focus groups shared that GPs treat people differently if they have LEP and emphasised that they are already judged before the appointment. For many participants, this resulted in concerns that they may be overlooked or dismissed, as "GP services don't want the hassle". As a result, some participants shared that they choose not to go to the GP as they feel they are not heard or seen properly.

"I experienced rudeness from the staff but I felt I couldn't record any experience because it felt like [it was] my word against theirs."

- People seeking asylum focus group participant

"It depends on the person. Some are very nice and would give you a translator. Others will say no. Racism is a huge factor."

- Roma focus group participant

"GP services don't want the hassle and send you to the pharmacy."

- Bengali/Sylheti focus group participant

"When people go to the GP, we worry we might not be looked after or overlooked."

- Somali focus group participant

"I felt dismissed and treated less than because, while I can understand English well enough, I am not as confident speaking it."

- Mirpuri/Urdu focus group participant

"They see I am Romanian and they don't want to help."

- Roma focus group participant

"They respect you more if you are educated."

- Somali focus group participant

In order to mitigate this, some participants attended with a family member or friend who spoke more proficient English than them.

"When you are with someone that speaks good English the doctor will hear issue with concern and listen. You don't feel seen if language is not fully there."

- Somali focus group participant

However, the family member or friend a patient chooses to take with them is unlikely to be a qualified translator with understanding of specific medical terms, which may at best result in misunderstandings and, at worst, serious harm. There can also be an added feeling of "being a burden" on family members and friends, leaving people having to "think twice" before accessing healthcare services.

Equally, this leaves those without a family member or friend with a stronger grasp of English to continue facing challenges, and arguably discrimination, when seeking to access health and care services, further widening healthcare inequalities.

Many participants in the Somali group related to the experience of not feeling listened to or looked after by their GP. They shared that they were regularly only offered paracetamol and felt that GPs treat people differently if they are not educated or have LEP and are already judged before they appointment starts. At times, this results in needing multiple repeat appointments, or their relatives intervening for their symptoms to be taken seriously.

One woman in the Bengali/Sylheti focus group shared that "when she takes her children with her, she is treated better because her children can speak English". Participants emphasised that "When you are with someone that speaks good English the doctor will take issue with concern and listen".

One participant in the Somali focus group shared that she went to see her GP with her friend who has a stronger English proficiency and acted as her translator. She tried to explain to her GP that she was having constant headaches, but her friend was not translating this properly, and the GP told her she had depression. She tried explaining that it wasn't depression but headaches, but the GP instead changed the word depression to 'anxiety', and she didn't understand what this meant. She was given medication for depression and told her daughter. In frustration, her daughter rang the GP and asked the GP to see her mother once more, explaining her mum's constant headaches. Only after this, she was asked by the GP 'how do you feel?' and was referred to a specialist who realised she had a serious physical health problem that needed urgent treatment.

Cultural understanding and discrimination, including gender appropriateness and differences in dialect

Bengali/Sylheti women, Somali women, and women seeking asylum, all experienced challenges with their assigned interpreter and cultural appropriateness regarding gender. Health and care environments should be considering patients' cultural and religious beliefs as part of their rights when receiving care. However, when this responsibility is not considered, individuals face yet another barrier when seeking to access health and care.

One participant in the Bengali/Sylheti focus group shared that she had a gynaecological concern but was not comfortable sharing this in front of the interpreter. As an alternative she tried to say, "I have some issue inside" but she felt too embarrassed explaining the concern further to the translator so did not get the help she needed from her GP.

A female participant in the Somali focus group had to cancel an appointment for a lower abdominal issue because the assigned translator was male. This case underscores the need for gender-sensitive translator assignments, especially for culturally sensitive medical examinations.

In contrast, one woman in the people seeking asylum focus group reported a good experience during a smear test, where the female nurse was understanding and supportive surrounding cultural sensitivities. This case demonstrates the positive impact of culturally sensitive healthcare providers and demonstrates the opportunity to expand this practice to translators.

Focus group participants shared that they are never provided with a choice of gender for their translator, and regularly find out at the appointment that they have been assigned a translator of the opposite gender. Some participants felt pressured to go ahead with the appointment, despite being

incredibly uncomfortable doing so for medical or cultural reasons, and so did not share their full concerns about sensitive or gender-specific health issues. Others shared instances of having to cancel an appointment due to being assigned a male translator and wait “up to two months” for a new appointment.

“It can take longer, go back and back again until we get actual help. I waited six months.”

- Somali focus group participant

All focus groups flagged concerns regarding regional differences in dialect when accessing translation services in a health and care setting, for example, a participant in the Somali focus group shared that Somali spoken in the capital Mogadishu is different from the East or North regions. Similar was heard from the Roma community focus group, with some individuals speaking Romanian and others speaking Romanes. Equally, most Sylheti’s can speak Bengali, but often Bengali people cannot speak Sylheti. Further to this, all participants in the Mirpuri/ Urdu focus group relayed that there have been times when they’ve requested Urdu and received Hindi or other languages which are similar but do not understand dialect nuance.

“If we don’t understand someone’s dialect we want the choice of another person we can access. Mostly qualified translators are good but do not all fully understand Somali.”

- Somali focus group participant

One focus group participant in the Polish focus group shared that when the assigned translator can understand and communicate in the same dialect, “it makes a lot of difference”; they feel “comfy and secure”, “listened to” and “feel heard”. Another participant shared that the first time they felt listened to when seeking their son’s autism diagnosis was when they had an Eastern European psychiatrist, who understood their dialect and cultural norms.

“I have seen a nurse that speaks my languages and could explain what I needed in my own language so I was heard.”

- Somali focus group participant

Unfortunately, whilst participants from some of the other focus groups shared that they had also attended a health and care appointment with a clinician who spoke their language and more specifically their dialect, the willingness to do so is not a universal experience.

In relation to Bengali health and care staff - “They’re in positions to help people, and even though they can obviously speak Bengali, they’re choosing not to. It’s not acceptable.”

- Bengali/Sylheti focus group participant

Individuals in the Bengali/Sylheti focus group shared that they have communicated with receptionists and doctors who they know are Bengali, but only communicate in English. The participants did not understand why this was, sharing that “they’re in positions to help people, and even though they can obviously speak Bengali, they’re choosing not to”. One participant had been told “that’s not my job” by doctors who can speak Bengali but would only communicate with a Bengali patient in English.

Whilst it is recognised in *Guidance for commissioners: Interpreting and Translation Services in Primary Care*, that bilingual professionals and primary care staff “should not, other than where immediate and necessary treatment is required, take on the role of an interpreter unless this is part of their defined job role and they are qualified to do so”, this was not effectively communicated to focus group participants. This misunderstanding between clinician and patient undoubtedly causes confusion, frustration and mistrust.

Intersectional discrimination

Participants from the Somali, Polish, People seeking asylum, and Mirpuri/Urdu focus groups all shared instances of intersectional discrimination, in which they felt discriminated against for multiple factors at once.

A disabled participant in the Somali focus group shared that when she went into hospital for a C-section, she faced judgement from the healthcare staff regarding her choice to have another child as she is disabled.

Similarly, one participant in the people seeking asylum focus group shared that she was not supported in her need to use a wheelchair in hospital. She shared that the healthcare staff told her to walk by herself, resulting in her fainting. During her two-week stay, she experienced racism and discrimination, and felt extremely vulnerable. However, she felt she could not record or complain about her experience as it would be her word against the health and care staff.

A participant in the Polish focus group shared that they felt they had faced discrimination due to their gender and LEP when seeking a diagnosis for their ongoing symptoms before finally being diagnosed with endometriosis.

A woman in the People seeking asylum focus group had a similar experience of underestimation of women’s pain. During labour, the participant was screaming in pain. However, as there was no translator present the healthcare staff wrongly assumed she was loudly speaking in her

primary language, and went to fetch a translator leaving the participant to experience a longer wait to be provided with pain relief.

A female participant in the Mirpuri/Urdu focus group, who had strong English proficiency, was giving birth and needed an emergency C-section. Due to this news, she required some time to digest the information before responding to the healthcare practitioners. However, based on her momentary silence and lack of reaction, as she needed time to process this information, the healthcare team assumed she couldn't speak English and brought an Urdu interpreter. She was not asked beforehand whether she required an interpreter, and this assumption meant her husband was excluded from the conversation. The participant shared that she felt this was a racist bias. She emphasised that because she dresses modestly and took her time to process medical information and decisions, they assumed she is uneducated and can't speak English despite speaking it with the healthcare staff beforehand.

Experiences like the above case studies add further context to the most recent MBRRACE-UK data, which found that compared with women from white ethnic groups, Black women were 2.8 times more likely, and Asian women were 1.7 more times more likely, to die during or up to 6 weeks after pregnancy³⁸. Similarly, in 2017, NICE found that the average time to an endometriosis diagnosis is 7.5 years in the UK³⁹. It can be argued that this is due to the persistent challenges women face in having their pain recognised⁴⁰.

"When I go to the GP, I am ignored, and the pain is brushed to one side. I am just told to take painkillers."

- Somali focus group participant

Wellbeing

Participants in the Roma and People seeking asylum focus group emphasised the consequential mental health and wellbeing challenges

³⁸ MBRRACE-UK. (2024). Maternal mortality 2020-2022. Available at: <https://www.npeu.ox.ac.uk/mbrrace-uk/data-brief/maternal-mortality-2020-2022#:~:text=Maternal%20mortality%20rates%20UK%202020%2D2022,-Overall%20293%20women&text=Thus%2C%20in%20this%20triennium%20272,%25%20CI%2011.86%2D15.10.>

³⁹ National Guideline Alliance (UK). (2017). Endometriosis: diagnosis and management. National Institute for Health and Care Excellence (NICE).

⁴⁰ The Lancet. (2024). Gendered pain: a call for recognition and health equity. Available at: [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(24\)00137-8/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(24)00137-8/fulltext). (Accessed: 25 October 2024).

which result from barriers faced when looking to access health and care with the support of a translator or interpreter. As some participants shared, they then have to deal with poor mental health on top of their original concerns surrounding their physical health.

"When we go to the doctor and we struggle to be understood we panic. It is stressful."

- Roma focus group participant

"I feel safer having a GP visit my hotel as I don't have to travel to GP, but I know only some hotels have it and some don't."

- People seeking asylum focus group participant

People seeking asylum also shared that they worry about advocating for their translation and interpreting needs due to their immigration status. This vulnerability exacerbates mental health symptoms further.

5. Quality of translators and interpreters

Misinterpretation and mistranslation

Participants across all six focus groups had experienced misinterpretation in health and care settings. It was shared that they felt the majority of translators do not translate properly, and many do not speak fluent English, resulting in them being unable to proficiently translate specific medical terminology.

A participant in the people seeking asylum focus group shared an experience where the GP was bilingual in English and in the patient's primary language and was correcting the translator who was making mistakes and using the wrong medical terminology. Understandably, the patient felt this could have been extremely dangerous and harmful if the doctor hadn't been bilingual.

A participant in the Roma focus group also shared that it is not just about the translator being fluent in English. They shared that translators need to have specific knowledge surrounding medical terminology due to the complexity of issues, nuances in language, and serious harm that may occur due to mistranslation.

Participants across focus groups also shared their experiences of translators bringing their own assumptions to health and care appointments, skewing what is relayed to the GP and resulting in patients feeling anxious when communicating with a GP through a translator.

Inappropriate behaviour and training of translators

Inappropriate or unprofessional behaviour from translators encourages mistrust, and results in patients asking their family and friends who may speak more English than themselves, to accompany them to translate instead.

Participants from the Somali focus group highlighted previous poor experiences when accessing translator services, and so they resort to having to trust their children to interpret for them. Poor experiences included translators arriving late to their already time-limited appointment and providing incorrect translation resulting in misinformation that could be detrimental to their health and cause serious harm.

On top of mistranslation, participants in the Polish focus group shared further examples of translators engaging in inappropriate behaviour. In one instance, an interpreter arrived under the influence of alcohol, almost an hour and a half late to the appointment. Another participant shared an experience of a translator playing games on their phone when they were supposed to be translating during a healthcare appointment.

There is also a vital need for a translator to understand how to disclose a diagnosis and translate sensitively as this communication is pivotal to patient experience and wellbeing. A participant shared that his friend's mother attended an appointment with a translator and were very abruptly told 'you have mouth cancer', which was understandably very upsetting. When translating life-changing and very sensitive information like this, it is crucial for empathetic care to not be lost in these interactions. In National Voices' report, [People's experiences of diagnosis](#), several members share examples whereby people found that when told their diagnosis staff were unsympathetic and failed to take account of the impact of the news.

Privacy concerns

Participants across the People seeking asylum, Somali, Bengali/Sylheti, Mirpuri/Urdu, and Polish focus groups, also all had concerns surrounding privacy, sharing that they worried translators may share their information, especially if they are from their community. In one example, a translator was known by the patient, and they felt uncomfortable and couldn't continue with the appointment. This concern may lead to patients not sharing all relevant information.

"I don't know if [the interpreter] will share my information – I knew a translator and I felt uncomfortable with that and felt I couldn't continue with the appointment."

- People seeking asylum focus group participant

"People have to keep telling their story to multiple people. If there is a different interpreter every time then there is lack of trust, how confidential are interpreters? I feel more people than necessary know my information."

- Polish focus group participant

Participants in the Somali focus group shared that they fear using a translator due to concerns that the translator knows their name, which may result in "their problem [being shared] around the community".

A participant in the Polish focus group shared concerns surrounding their privacy given they see a different interpreter with each appointment. They question the confidentiality of their information when more people than necessary know their medical concerns.

6. Carers

Focus group participants shared both negative and positive experiences regarding engaging with the NHS as a carer. We heard from a number of people who cared for young children or family members. Their experiences are highlighted throughout the themes above, but it is important to note the added feeling of responsibility when trying to help someone else. Many of the carers we heard from mentioned feeling "stressed and under pressure" to ensure their loved ones are able to access healthcare services in a timely and appropriate manner, even though they may not go the same lengths to access such care themselves. In one example, a participant from the Mirpuri/Urdu focus groups described how their mother felt "helpless" as she couldn't access health and care by herself simply because she could not speak English.

In relation to advocating for your own health and caring for children - "You have to struggle with an illness."

- Bengali/Sylheti focus group participant

Mental health concerns are taboo in the Somali community, and participants seldom want other community members to be aware of the challenges they are facing. In this case they would be more comfortable with a translator they weren't related to (such as an unpaid family carer). This ensures they are able to discuss their concerns more freely in an appointment, mitigating the worsening of such mental health challenges.

One participant from the people seeking asylum focus group shared that when attending an appointment with her mother as a carer, the healthcare

staff present expected her to translate. When she was hesitant regarding her understanding of medical terminology, the healthcare staff encouraged her to keep going, and did not provide an opportunity to flag this discomfort or offer a translator/interpreter.

In contrast, the Mirpuri/Urdu focus group shared that one of their local GPs hosts carer support groups. However, the participant who shared this had a higher level of proficiency in English, so needed little support to help integration into the support group.

Recommendations

1. Patients must be offered choice in how they want to communicate with the health service, with their access and communication needs clearly recorded on their health records

Language needs should also be extended to include dialect. Choice of interpreters should include gender, language and dialect, and details of the translator should be shared prior to the appointment, with the patient given the opportunity to request an alternative translator if required. Continuity of care through provision of the same interpreter will also be better supported by offering patients choice in their translator where viable.

As part of improving patient choice there will be a need to review how long appointments should be when an interpreter is required, and this automatically factored in when offering appointments. There must be increased access to translators for out of hours appointments to reflect the impact of working and caring responsibilities, and access to online e-Consult forms should be extended into the evening to allow people to seek help with translation where needed.

2. Translated personalised communication should become the norm

All focus group participants requested to view their health records and notes in their native language, recognising that it would help them to better manage their own health and feel safer in following instructions about next steps.

Equally, people should be able to access personalised communication, such as text reminders, in their native language. The first recommendation surrounding recording a patient's access and communication needs, specifically their chosen language, on their health records, explicitly lends to this.

For those who do not communicate in a written language, we recommend offering video resources or information communicated via telephone. While we recognise this recommendation would be a step change in interpretation provision, we noted from our focus group engagement that a similar service is provided by other public services such as universal credit decisions. A later recommendation also highlights the opportunity to collaborate with community groups to support people in understanding their rights. Similarly, services can collaborate with community groups to produce video resources.

3. Quality of translation and interpreting services must improve and the system better regulated

The poor quality of translation services must be improved to increase trust and reliability in the system. The service must be professionalised through regulation and registration of suitably qualified translators, all of which must demonstrate a fluent

understanding of medical terminology. Translation agencies must be held accountable for ensuring translators are prompt and adhere to clear translator/doctor/patient confidentiality, as outlined in the General Medical Council's Good medical practice resource, with patients being able to provide feedback and raise concerns about their interactions with the service⁴¹. It may be necessary to review pay structures for translators to ensure it attracts professionals and to consider more creative ways of making local translator provision cost effective, for example by creating translator hubs that work across multiple local services, such as health, policing, and local authorities.

It is essential that the Government's 10-year Health Plan mandates the provision of Community Language, Translation and Interpreting (CLTI) services within NHS services for marginalised communities and seeks to standardise both access to, and quality of, this service.

4. High quality cultural competence training for health and care staff

A consistent theme from our focus group work was people feeling they are being denied access to a translator by services and professionals because of systemic racism. Due to the persistent racial discrimination that takes place in healthcare settings, we recommend high quality cultural competence training for health and care staff, which may be coproduced with VCSE organisations. Clear escalation pathways should also be put in place for those who discriminate.

5. Mitigate against digital exclusion

It was clear from our focus groups that there is an overreliance on AI translation tools such as Google Translate, that often result in inaccuracies and in some cases creates unsafe care. Those that found it most useful already had a higher-level of English competency. Creative solutions to the shortage of professional interpreters should be reviewed without an automatic default to AI as a remedy to these concerns. This recommendation also emphasises the obligation for all NHS services to implement the principles and practices set out in [NHSE's Inclusive digital healthcare framework](#).

Separately, the NHS should leverage the commercial value of working with the NHS to engage and encourage technology companies to improve how AI solutions can work with non-Western languages, as well as trialling their use to translate personalised patient materials as outlined in recommendation two. The NHS App must also be made available in different languages with a clear timeline mapped out to do so.

⁴¹ General Medical Council. (2024). Good medical practice. Available at: <https://www.gmc-uk.org/-/media/documents/good-medical-practice-2024---english-102607294.pdf> (Accessed 09 January 2025).

6. Create and upskill diverse healthcare teams that reflect the communities they serve

All focus groups found that diversity in healthcare teams improved their ability to communicate, although there was a very mixed response on whether bilingual NHS staff offered to help translate for them. While we recognise NHS England concerns that staff should not act as translators, this binary approach is not working well in practice, with staff often feeling like they want to help their patients better understand what is happening to them, especially during inpatient or unscheduled care where booking translators in advance has not always been possible. One solution would be to offer to upskill bilingual staff in the health and care environment, from clinicians and receptionists, to catering and cleaning staff, to qualify as professional translators. This approach will not only widen the pool of available translators, but may also encourage staff retention.

However, it may also be appropriate to review medical professionals' liability if acting as translators for patients so the NHS can maximise a patient's understanding of their care without unfairly jeopardising bilingual staff members who step up to help.

7. Collaborate with community groups to support people in understanding their rights

Although a handful of focus group participants understood their legal rights regarding access to an interpreter, few felt able to advocate for themselves. We encourage NHS England to collaborate with community groups to help patients understand their rights and to help support them in exercising them.

We also recommend that, as with people experiencing homelessness, GP surgeries cannot turn away an individual who is asking for support to access care on the basis that staff in the health and care environment do not understand them. We urge the NHS to create resources similar to the homeless charity Groundswell's 'My right to healthcare' cards, which can be adapted to languages needs⁴².

Finally, working with the third sector will be vital in communicating positive changes in translation and interpreting services, to help build trust in people using these services.

⁴² Groundswell. (2019). 'My right to healthcare' cards. Available at: <https://groundswell.org.uk/resources/healthcare-cards/> (Accessed: 25 October 2024).

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National Voices

National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 200 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

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