

# **Lost for words**

**Healthwatch Evidence on how language barriers contribute to health inequalities**

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# Executive Summary

The [Accessible Information Standard](#) (AIS) ensures people with a learning or sensory disability can understand and communicate with healthcare providers. However, it does not currently cover the needs of people who have limited or no English.

Our research delves into the experiences of people from minority ethnic communities who live in England and find it challenging to communicate with the NHS because they don't speak English well or at all. We also look into the issues faced by healthcare staff when caring for such people.

With the help of six local Healthwatch, we interviewed 109 people and 38 members of staff between October and November 2021. We produced our interview guide following discussions with the local Healthwatch and a panel of "experts by experience" from [Doctors of the World](#) – an independent humanitarian movement that aims to empower excluded people to access healthcare.

Our evidence concluded that people who experience language barriers struggle at all points of their healthcare journey. They find it difficult to register with a GP, access urgent care, navigate large healthcare premises, explain their problems, or understand what the doctor says.

Lack of interpretation support further compounds their issues. They may not be aware of professional interpreters, find it difficult to access one when needed, or even understand them if interpreters don't speak their dialect. As a result, they don't get the healthcare that they need.

Some people preferred to use family or friends to translate for them, but others felt uncomfortable doing so. We also heard that cultural and privacy concerns can affect someone's preferences, for example women wanting same sex interpreters. Whilst staff were keen to use technology to translate, some people with language barriers didn't have confidence in it.

Staff told us that there were no common systems for recording people's language requirements or sharing this information with other parts of the healthcare system. Staff wanted more training and support to help people with language barriers. Staff also felt constrained by ever-reducing budgets for interpreting. The consequences of not having these in place included people missing appointments or experiencing delays to their care.

Staff, patients and family members made suggestions for change which would improve their experience, including automatic alert systems to flag people's language needs, easier access to translated resources, and flexible support based on individual needs.

We recommend that the existing guidance for commissioning interpreter services in primary care becomes a statutory obligation for all healthcare providers. We also recommend providing more coordinated interpreting and translation services at the new Integrated Care System levels.

# Background to our research

NHS England (NHSE) implemented the [Accessible Information Standard](#) (AIS) in 2016. It makes it mandatory for all health and social care providers to ensure that people with a disability or sensory loss can access and understand information and communicate effectively.

NHSE is currently undertaking a review of the AIS and will publish a report in spring this year. They have also acknowledged the need to address the issues of people who have limited or no English and will investigate them separately.

To feed into their review, we examined [our network's evidence](#) to determine how people's experiences had changed due to the AIS. We also looked at how the pandemic impacted their communication support. While some providers had taken significant measures to support people with communication needs, we found that many were still falling short.

Our report also highlighted that the AIS does not cover all people who find it challenging to communicate with healthcare providers. One of the groups that stood out the most were people who had limited or no English. These are often some of the most vulnerable in our society, for example, refugees and asylum seekers. Lack of English puts them at a more significant disadvantage and contributes to health inequality.

Therefore, we focused our research on people who experience language barriers in accessing care and treatment to understand how it impacts their healthcare experiences and outcomes. Additionally, this research allows us to explore an important issue many people from ethnic minority communities in England face when they contact healthcare services – the services' failure to communicate with them in an accessible way. This research strongly aligns with our [organisational strategy](#), which aims to amplify the voices of communities whose views often go unheard, overlooked, or ignored.

We grant funded six local Healthwatch who interviewed **109 people**, all from minority ethnic communities, to share their experiences of accessing healthcare services. All our research participants were people who had limited or no English.<sup>1</sup> Local Healthwatch also spoke with **38 staff members** working in different healthcare settings. See the section at the end of this report for more details about our research methodology.

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<sup>1</sup> Note: Language translators helped local Healthwatch carry out most of the interviews. Hence, there may be interpretation bias in the evidence.

# When do language barriers affect access?

We found that people faced problems at all points of their healthcare journey.

People with limited or no English face significant difficulties registering themselves and family members with a GP without appropriate language support. One research participant couldn't register their child and had to seek healthcare privately. Another had to change their surgery as they couldn't communicate with the receptionist to request an appointment. As a result, they faced delays in getting help.

When people finally see the doctor, they have difficulty explaining themselves without interpretation. The individual might not understand what the doctor said, such as why their medication was changed or discontinued. As a result, they feel anxious about their health.

"I have regular consultations every three months, and the conversation is very short and usually the same: what's my medication, how do I feel? Do I have bleeding etc.? I usually respond with yes or no. Sometimes I feel like they treat you as you are in a slaughterhouse. One comes, one goes. I don't feel that I am in safe hands, but I have no other options from the other side. Although the appointments are routine, sometimes I may have questions that I want to ask, but I can't because I wouldn't know how to say it in English. So, I keep quiet." Russian woman who spoke to Healthwatch Norfolk

Access to urgent care services can be challenging if there is no way to recognise people's language needs and provide adequate support. For example, calls to NHS111 can be much longer. Several participants said they often do not understand the information they hear when calling NHS 111. Some end up in A&E, where they struggle again to express their concerns. In one case, a mother had to resort to writing the issues about her autistic son when he needed urgent help.

"Her son has got autism; he needs emergency help. And the second time, she said she had to write what she wanted to say to the doctor because of the language problem. In an emergency, she had to write it, and she's very upset about that, that she can't explain it to the doctor." Tamil translator for Healthwatch Croydon's focus group

Getting to a hospital appointment is challenging when people don't understand the appointment letter. They find it difficult to navigate large hospital premises or know which department they need to attend. Our evidence indicates that hospitals don't often send location details in the patient's language, probably because their records don't highlight their language needs.

Our evidence review related to the AIS found that the pandemic had exacerbated access to interpreting services.<sup>2</sup> People with limited or no English faced particularly acute problems. Some struggled to book appointments over the phone as they didn't understand pre-recorded messages or which buttons to press.

Patients couldn't explain their exact symptoms without support for their language needs due to their limited English. In turn, this worsened their condition.

“During the pandemic [participant's] eczema got worse, and she tried explaining her symptoms to a doctor and interpreters were never used. He repeatedly gave her creams. She could not explain herself, and the condition got worse, and this resulted in the area becoming infected and worsening the condition.”  
Bangladeshi translator for Healthwatch Liverpool's focus group

The NHS Race and Health Observatory has also reported that people from ethnic minority communities are less satisfied with telephone triage systems in GP surgeries compared to white people.<sup>3</sup> It is very likely the dissatisfaction stems from the lack of understanding of the systems due to language barriers.

# What type of barriers do people face?

## System related barriers: access to interpreters

System-related barriers are the most common type of barriers people face. It is possibly the easiest type to address as well. People who don't speak English well enough to communicate with healthcare services need help from interpreters. However, they are either unaware of interpretation services or have difficulty accessing them.

## Lack of awareness about professional interpreters

People with limited or no English may not be aware of interpretation services because of a lack of accessible information. Several of our participants didn't know they could ask for help for their communication needs. As a result, they had

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<sup>2</sup> [The Accessible Information Standard, Healthwatch England, February 2022](#)

<sup>3</sup> [Ethnic Inequalities in healthcare: a rapid review, the NHS Race Observatory, February 2022](#)

never used NHS interpreting services. Moreover, those who were aware knew of such services at hospitals but not at GP surgeries.

“I wasn't aware that I can request support around interpreting. I only thought that this is available through the hospital and only if they think it is necessary. I thought it's only for midwifery because the only one who brought me an interpreter was the midwife. Often my husband had to skip college to come with me to appointments.” Arabic woman who spoke to Healthwatch Hackney

There are other reasons why some people do not ask for help from interpreters. For example:

- Some patients may be aware of services but may not know how to book an interpreter in advance.
- Some people, especially women, feel too shy to ask for help. Others may not feel confident in their English to ask for an interpreter or feel the providers will refuse any help if they do so.
- Others think it'll be a waste of time because they won't understand what the interpreter says.

Our evidence clearly shows that when people do not seek help due to a lack of awareness, they struggle through their appointments.

“I would never even imagine that such services like interpreter can be possible at the hospital, so I was always relying just on myself struggling through all that appointment to explain and to understand properly how the treatment should be taken, prescription, and what to do next, so difficult.” Ukrainian man who spoke to Healthwatch Croydon

## **It's not always easy to access an interpreter**

Lack of access to official interpreters can deter people from accessing different healthcare services. During their conversations with the research participants, Healthwatch Liverpool found that often people didn't get an interpreter because staff refused to book one or they weren't available. Even when staff had booked an interpreter, there was no guarantee that they would provide support. We heard that sometimes interpreters didn't turn up or speak the same language or dialect as the patient.

Access to an interpreter can be more difficult for a face-to-face appointment than a phone appointment because staff need to book the interpreter in advance. Several participants pointed out that the pandemic has made

accessing an interpreter for remote and in-person appointments more difficult. People found it more challenging to get an interpreter for GP than for hospital appointments.

“At the GP surgery, we never received an interpreter, but at the hospital, we do manage to have one all the time. Even over the phone to get an interpreter.” Romanian man who spoke to Healthwatch Norfolk

As a result, some made their own arrangements. We heard this could take time and may not be free of charge - one participant asked someone from their community to help and paid them for their time.

When people cannot make arrangements, they might be put off seeking help from the NHS. We heard about alternative solutions, such as asking relatives from their home country to send them medicines.

“The two main problems I always meet, the first one is that I always need to find somebody who speaks English before I contact the NHS or before I look for any help from doctors, and it creates lots of discomfort because I have to find somebody who speaks English, who has time, who is ready to help. People are mainly busy with their own duties, work, and I have always relied on somebody, and it creates a big discomfort. Also, sometimes I don't even call NHS at all, I ask my relatives from Ukraine to pass me some medication from Ukraine, so I don't call the NHS at all.” Ukrainian man who spoke to Healthwatch Croydon

## System-related barriers: quality of interpretation

Our participants reported mixed experiences of using an interpreter during healthcare appointments. Some felt they could not explain anything without an interpreter. They felt better understood when an interpreter was present. One person thought that they received better treatment when they had an interpreter. Others weren't sure if their presence significantly affected the quality of communication with healthcare staff. Poor quality interpretation has meant that a person left their appointment without knowing what was said.

“There was a Turkish Cypriot interpreter over the phone, and I understood nothing but was only saying OK. I left the session without a clue. I went there because I wasn't feeling well. I guess it was my blood pressure. But I didn't say anything to the doctors because there was no point.” Turkish speaker from Hackney

## Language and dialects

Some languages have a variety of dialects. Interpreters who do not speak the same dialect aren't very useful. Several research participants said their communication problems weren't solved when the interpreter spoke another dialect.

"It is common for Bangladeshis to be booked interpreters from different parts of India. [Participant] explained how some interpreters were from Calcutta, which is in India, not Bangladesh and therefore spoken completely differently. Sylheti dialect is a different language to the language spoken in Calcutta." Bangladeshi translator for Healthwatch Liverpool's focus group

"I don't know if they actually understand me because I'm Syrian. They bring an Iraqi, a Moroccan, Tunisian [interpreter]. The dialects are different, and that's a struggle." Syrian woman who spoke to Healthwatch Reading

When people can't rely on getting an interpreter who speaks the same dialect, they might not even ask for help.

Healthcare services might not differentiate between dialects if the patient record systems that they use don't have fields to collect this information. For example, one trust reported not having anywhere to store information about a person's primary language, only their country of birth. Even if the system does have fields to collect people's language needs, staff may not remember to complete them.

## Other issues about the quality of interpretation

We heard about other situations when the quality of support from interpreters wasn't as people had expected:

- Some of our participants felt rushed by the interpreter to finish their appointment as quickly as possible because their agency had booked them to support several people on the same day at different practices.
- Interpreters may be fluent in the language, but they may not understand medical terminology well. As a result, people feel unsure if the interpreter has correctly interpreted what the medical professional has said.
- Some participants felt that interpreters didn't understand the gist of what the doctor said. For example, an interpreter told an individual that they might die when the doctor had said their condition was severe but not fatal.
- On occasions, some interpreters respond to the doctor without even asking the patient, making people question their reliability.

## System-related barriers: lack of translated information in other languages

People who cannot read English aren't given written information about their conditions or medication or access information online about health-related queries and appointments in their language.

We have also heard that translated information that includes complex terms without explanation may not help people understand what action to take. For example, a Yemeni woman mentioned that the information she received had Arabic terms that were difficult to understand.

When people don't have access to information in the language they can understand, they create their own solutions. One participant asked the doctor to write their advice in English and then looked for someone to read it and translate it. People take risks by acting late on medical advice, if they don't get healthcare information translated quickly.

Without access to translated information, people also take risks by self-diagnosing or self-medicating without consulting their doctors. One of the participants from Healthwatch Liverpool's focus group said that she often uses the internet to search for answers about her health condition in her native language. She said she does this because her GP doesn't provide any information in her native language.

Access to information in other languages was particularly challenging during the pandemic. Some of our participants said they used social media to search for information.

"(...) when I don't understand what the doctor is trying to tell me, I will ask them to write me a letter and then I can take that letter to someone to explain to me exactly what the doctor is saying. Yes, it has actually had a negative effect on my health. Because sometimes I get a letter in my hand. By the time I look for a suitable person to explain to me, because I don't want to give it to anybody, so by the time I look for the person that I trust the most to explain, sometimes it's too long and then the doctor will write to say that I have to re-start everything from scratch, and that is the consequence. Or sometimes, by the time I get somebody, it can actually cause me some problem as well." **French-African speaker who spoke to Healthwatch Croydon**

## System related barriers: different systems not talking to each other

Our evidence tells us that there is no coherent process or system for all services to help people with limited or no English. Different trusts and care services use different operating systems and software, and they don't seem to work well together. For instance, staff couldn't copy patient information between [Cerner](#) and [InfoFlex](#) systems, so they had to record information separately in each.

Staff told us that there are different ways of recording patient language needs. As a result, information is not always communicated effectively between the various systems and services, often leading to patients' needs being missed or overlooked.

Further examples:

- Some trusts don't have a flagging or alert system to make them aware of patient language needs before appointments, leaving them unprepared.
- Staff often record language needs in the notes within electronic records. But there is no guarantee that clinicians, who don't routinely scroll through the notes, will read this.
- Some departments or services keep their own notes separately and may not always share them with others. It becomes an issue when the individual has to visit multiple departments for their healthcare needs.
- GP surgeries often record a person's language needs; however, some services have limited access to GP records.

"The issue we have is that there is nothing, no alerts on the system, that will tell us that this patient needs an advocate. We have to go into a particular area within the system to see the information. So, you may put it on the system as an additional note that their first language is Portuguese, but there's no alert."  
Booking Service Manager, Hospital in Hackney

## Staff-related barriers: lack of clarity around people's language needs due to inadequate support for staff

Staff recognise that the support for people with no or limited English could be much better. However, they aren't always sure how to provide it. Several said they needed better support to help people in this situation communicate. We heard that there is no clear and consistent approach to identifying and recording a person's language support needs. Some felt that they do not have the right tools and processes to deliver a consistent service:

"I think it [language needs] should really [be covered by the AIS] because I think in the long-term, if you don't support people with these needs, then often, you know, they may not understand

what's going on. If they don't understand, they might not attend examinations. They might not attend investigations like MRI scans. And they will end up bouncing back into the health service at some point, either because they're in a more acute situation or their GP's referred them back." Admin Team Lead for pain services in Reading

Staff from all services emphasised the importance of identifying language needs at the first point of contact. However, processes aren't always in place to allow them to do so. Consequently, they don't have time to prepare, impacting their ability to provide support. Staff attitudes towards people with limited or no English may also be affected.

"So we've got a guy who can't speak English standing in the foyer, and all he wants to do is speak to somebody who can explain things to him, but he can't ... he wants to come in to talk face-to-face, so we've got to try to explain to him, in the meantime, the receptionist in the front is dealing with about five other things, now if you're dealing with somebody who can't speak English, then it's frustrating for both people, it's hard for everybody ... you have to be a welcoming face, that's not looking and going '[exasperated sigh] ah I haven't got time for this.'" GP Practice Reception Manager from Liverpool

## Staff-related barriers: issues around support from GP practices

GP services are the initial point of contact for patients. Feedback from GP practice staff emphasises their essential role in making sure people with little or no English receive the proper support. When people visit a GP surgery, they interact with reception staff first. Receptionists, therefore, play a crucial role at the very start of people's healthcare journey. However, it is not clear from our evidence whether they receive any training to identify and support people with limited or no English.

In our patient interviews, we encountered several instances where people have found GP receptionists particularly unhelpful. A few have even felt their attitude discriminatory. Lack of awareness and adequate training can impact staff attitudes.

We need proper training. You get training for people who've [got] disabilities, you're told, 'don't speak to the parents, speak to the person with the disability.' You just know these things, but you don't with people who don't speak English, and there are a lot of people here now who [don't receive] the kind of treatment

they need. Former Reception Manager, currently Patient Liaison Officer for a GP Practice in Liverpool

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GP practice staff reported several different ways to identify and support people with limited or no English. For example,

- In some cases, it is up to the person to provide details about their first language and whether they need support.
- Some practices encourage online registration or direct patients with limited or no English to the website to complete a form about language support requirements. Yet, these websites are only available in English.
- One GP staff member told us that there are different ways of flagging language support needs even within their own practice. While some can record the information on a "list of problems" page, others can place a flag on the system. Some even ask the patient every time they visit and note it on their record. Others mentioned that reception staff could rely on physical cues to indicate that the patient may need language support services, e.g., noting if a person uses translation apps on their phone or has a family member accompanying them.
- Another GP staff member said they deal with patient language needs on an "as and when" basis.

Consequently, they may not record at all or misrecord a patient's language needs at the beginning of their healthcare journey. As a result, the person's needs can be overlooked, which can have a knock-on effect on access to treatment and other services.

Relying on patients to be proactive and ask for help can be unreasonable when they may not even be aware of interpretation support. They might not access or complete online forms that aren't available in their own language. During the pandemic, the lack of face-to-face contact exacerbated those issues as staff could not identify language support needs as easily.

Staff mentioned challenges for walk-ins and urgent appointments, as there is little time to prepare. They feel they 'muddle through' on such occasions. Some said that interpretation services must be booked at least a week or two in advance, so it is impossible to support people in urgent situations.

"Usually, if they [patients] are booked in, we keep an eye on our clinics to see who is coming, and we can pre-warn them [interpreter services] that I am going to be calling you later, but it doesn't always work like that because if it is an urgent thing, you do not always have time to pre-sort it all." – Primary care clinical staff who spoke to Healthwatch Norfolk

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## Impact on other services

We heard from staff working in various referral services who relied on GPs to flag language needs ahead of appointments. Staff told us that information is often auto generated from GP systems and may not always contain the needed details. Also, GPs may record languages but not specific dialects. Sometimes language needs are not recorded at all.

Consequently, this impacts other services' ability to support communication needs. For example, referral services can't ensure that patients are sent information in their own language about appointments. As a result, patients miss appointments or do not receive any language support during the appointment. We heard from staff that appointments get cancelled, and they have to rebook them to make sure an interpreter can be present. It can lead to delays in accessing care and treatment.

## Staff-related barriers: staff are willing to use technology, but it may not work for all

There was enthusiasm amongst staff about using technology to support language needs and a sense that technology has made communication more accessible and reliable. We heard that there had been a shift towards using digital services, such as LanguageLine, BigWord, and Google translate. There was also greater use of tablets and iPads to support communication, especially since the pandemic.

"We were blessed to have iPads and things to do FaceTime, not only for the family, but if we needed to use language interpreters, we could use it. It's never the same, like face-to-face, but at least we had a mechanism put in place." Nurse who spoke to Healthwatch Croydon

Staff felt that technology ensured that people could access help and interpreting services quickly, particularly in emergency settings, but it wouldn't work for everyone. Some felt that face to face appointments work better for people with limited or no English. Staff want the emphasis to be on individual choice.

"If you perhaps look at the Bengali community, maybe even the Turkish speaking community who perhaps tend to be slightly older women who perhaps aren't even well educated in their own mother tongue and it was a little bit more challenging, but we did find ways around it, and we did manage as best we could. Yeah, I think for some people they quite liked the video, but for many, they would have preferred face to face." Bilingual Health Advocacy Manager who spoke to Healthwatch Hackney

It is essential to highlight that although most staff were aware of the limitations of remote interactions with people who experience language barriers, some weren't. It raises the question of whether there is a disconnect between patients and providers about using digital platforms for consultations. Several participants said they find it more challenging to communicate digitally.

## Staff-related barriers: funding and costs

Many healthcare staff recognise the importance of language support and want to help patients but feel constrained by ever-reducing budgets for support.

Consultations for those who require language support are typically longer, more complex, and more costly. Trusts are often charged by the hour for interpreters, which can be expensive when there is no clear indication of how long appointments will last. It can discourage them from allocating funds towards interpretation services.

Some staff mentioned they could come under pressure if trusts feel they "over-use" interpretation services. On these occasions, departments can be flagged for using interpreters too frequently or asked to make sure they only use interpreters "if they really need to".

"In the past, there was budget for non-English speaking appointments which recognised they were more complex and needed longer consultations. But that seems to have disappeared. We would all advocate for longer consultations and more resources, but there's not enough doctors and not enough time." GP from Camden

It puts a strain on practitioners – especially during the pandemic – and means they cannot advocate for interpretation and language support, even if they would like to. It may also lead to greater reliance on technology for interpretation as this is typically a cheaper alternative to face-to-face services.

An analysis of responses from 115 NHS trusts to our Freedom of Information (FoI) requests found that there has been a 22% reduction in actual spending on interpreting and translation into non-English languages over the past three years.

Much of this decline in spending is likely to result from the impact of the pandemic. Fewer patients were attending hospitals, and there was a shift to online or video interpreting, which costs less. However, it is unclear whether patients can choose between online and face-to-face interpreting as the NHS returns to pre-pandemic service levels.

There is a risk that some trusts are switching to or maintaining online or remote interpreting as a cost-saving measure, which may not always work best for patients. We know that online interpreting does not always work for everyone, and some people can experience additional problems with booking interpreters online or over the phone.

In the future, it will be necessary for trusts to benchmark the number of interpreting requests against pre-pandemic demand and to take steps to ensure everyone is aware of their right to interpreting support when they attend appointments. NHS England should also provide clarity for providers around minimum standards of interpreting provision and the patient's right to choose between remote and face-to-face interpreting where appropriate.

## Patient-related barriers: personal preferences

People might have personal preferences about getting help for their language needs. We have come across various examples highlighting that people think differently about getting assistance with interpretation. While some prefer friends/family to support them during their healthcare appointments, others prefer a professional interpreter. Some might have no preference, while they don't like either in some cases.

Below we discuss the personal barriers the research participants told us about. Although this may not be an exhaustive list, we feel they indicate some of the issues providers must consider when supporting people with limited or no English.

### Using family or friends

Some people said that they feel more comfortable asking a friend or a family member to interpret for them than using a professional interpreter. People trust their family/friends, think they are supportive, have an emotional connection with them, and are more aware of their symptoms. As a result, people feel confident about their treatment and feel more optimistic.

Other reasons for preferring a family/friend as translators include:

- It can be easier to coordinate logistics with them than a formal translator.
- Family and friends can provide transport for people with mobility issues.
- People felt more comfortable talking about health issues, including mental health, in front of a familiar face than a stranger.
- People felt that the family member/friend would translate more accurately.
- In cases where the patient was elderly or had complex issues, the family member could be a source of memory and help explain the situation to the doctor.

"I would prefer my husband as I feel more comfortable with him. Even if there was an interpreter, I would still want him to come with me just in case." Kurdish Iranian woman who spoke to Healthwatch Hackney

It is interesting to note that all four family members who took part in our research said they preferred not to act as 'interpreters'. They mentioned various reasons, such as:

- Feeling they have an additional responsibility for their relative's health.
- Lacking the medical knowledge to provide the proper support.
- Not wanting to know about their relatives' health issues or tell them how to live their lives.
- Needing to take time off work to accompany their relative leading to loss of income. It isn't always easy to get an appointment outside their working hours.

“People continuously struggle to find someone to assist them; their children often get fed up with having to translate everything for their parents and other relatives. They lose interest in helping after a while. Sometimes one child says they do not want to do it; their sibling should translate instead. But generally, it is neighbours who are lumbered with helping.”  
Family member of a patient participant

### **Some patients have concerns about asking family/friends for help**

Some patients, however, told us they feel uncomfortable asking their family/friends for help with interpretation. Relying on them can make people feel guilty, embarrassed and inconvenienced, impacting their relationships. They may also not be available when needed, e.g. when urgent care is required.

Some participants pointed out that even when family and friends interpret for them, they may not know medical terms to interpret fully. Second-generation immigrant children may be more fluent in English than the language their parent speaks. As a result, they cannot support their parents with their language needs.

“A few months ago, suddenly I lost balance because I felt pain in my leg, so I fell off. I called the GP, who said I should go to the hospital, and she is sending them my information. My son called a taxi and took me there. When we arrived, I was asked to give a urine sample. But I was too stressed and scared. I was worried about what was happening with my body; I was nervous and wasn't able to give the sample. My son was talking to them, but I don't think he told them the right information. He has very good English but not that great Chinese. I, on my side, wasn't able to communicate with them due to my poor English. They then just assumed I was fine and sent me home without doing any checks.” Chinese man who spoke to Healthwatch Hackney

Asking for help may not be an option for people who don't have a suitable friend or a family member. Some participants felt their family/friend could compromise their privacy if they accompanied them to their doctor's appointment. They

could pass their private health information to others in their community. Others said they might not want their family to know about their health concerns.

"I would prefer an interpreter than my daughter as I don't want my health condition worrying her, and the interpreter will tell me everything." Chinese woman who spoke to Healthwatch Liverpool

## **Cultural and privacy concerns can impact on an individual's preferences**

Our research participants belong to various ethnic minority communities, many of whom have cultural influences on their lifestyle and choices. This might influence the type of interpreters that they want to use. For example, people, especially women from South Asian, Middle-Eastern and some African communities, prefer an interpreter of the same gender. It could be a relative or a professional interpreter, if they are from the same gender.

Talking about mental health is unacceptable in some cultures. Some participants have mentioned that they are less likely to seek help for their mental health issues even with interpretation support. Healthcare staff, therefore, need to be aware of cultural stigmas around mental health, as well as provide interpretation.

We heard that some people feel uncomfortable having an interpreter as they could compromise their privacy. They prefer to rely on their limited knowledge of English than asking a friend/family or even a professional interpreter for help.

"I try my best not to share my medical secrets with anybody, even if it means I will do all the gestures in the world so that the doctor can understand what I'm trying to say. I would because, you know, I'm a big man, I'm a grown-up man, I want to integrate, even with the very little English that I have. So, I don't use an interpreter because, you know, I want to keep my medical story to myself, my private medical illness to myself." French speaker from Africa who spoke to Healthwatch Croydon

## **Some prefer using technology, others don't**

Technology can help bridge the communication gap for some individuals with limited or no English, but not for all. Quite a few participants found translation phone apps, such as Google Translate, particularly useful. In one case, an individual uses their phone to record what the doctor said as an audio file and finds someone later to translate it for them.

In contrast, others felt technology was unreliable, as there is less dialogue between them and the healthcare professional. Using technology isn't feasible for people who aren't literate in their own language. Moreover, such applications may not be accurate and can cause further confusion.

“Once I had vertigo, I was throwing up and all these symptoms. The doctor gave me medication for my ear. I asked, 'can you explain more?' He went on and on, and I didn't understand. He printed me the pamphlet and said, 'read this at home'. I read it and can't understand it. I am not a scientist. I use Google translate for the printed materials, but sometimes it's not accurate.” South Sudanese woman who spoke to Healthwatch Camden

It is also worth noting that most of our participants did not find telephone appointments helpful, even when they had the support of a remote interpreter. This became a more significant issue during the pandemic when there was an increase in remote care provision.

## **Patient-related barriers: impact of staff attitude**

People with limited or no English are more likely to feel satisfied with the healthcare services when they are well-supported with their communication needs. When they feel understood, they are more comfortable and willing to engage with healthcare staff. For example, Healthwatch Reading found that language support helped Syrian refugees speak to people and access healthcare during their resettlement programme.

We have come across evidence suggesting some staff go out of their way to help people who do not speak English. For example, some were kind and easy-going and made every effort to understand the person, and others helped find an alternative solution when they couldn't arrange an interpreter. We heard of staff helping with the interpretation or providing a healthcare professional who speaks the same language as the patient. Supportive staff attitude encouraged people to seek timely care and made them feel safe.

Some providers also ensured continuity of interpreters so they could develop a trusting relationship with them during their healthcare journey, such as during pregnancy.

“She was very happy with her interpreter. She said she was lucky that the interpreter was continuous, the same lady through her pregnancy till birth. A good relationship with the patient, so she was very, very happy, anything she would tell her she would translate and get the message.” Interpreter for Syrian woman who spoke to Healthwatch Reading

In contrast, unsupportive staff attitudes can prevent people from seeking timely help. Several of our research participants have indicated feeling withdrawn, sad and unable to express themselves due to how staff treated them. Some also mentioned going back to their country of origin to get medical help because

they could not communicate and access healthcare in England. Worryingly, we have also come across evidence that suggests some staff are unwilling to help people access interpreters despite them asking for one.

"We stopped asking for an interpreter, and they never offered us one. I used to ask, but the receptionist told me a couple of times, "Your English is good; you don't need an interpreter"." Kurdish-Iranian woman who spoke to Healthwatch Hackney

Negative staff behaviours and attitudes can discourage people from seeking support. It contributes to people from minority ethnic communities feeling 'othered', unwelcome and poorly cared for.<sup>4</sup>

# Practical improvements patients, family, and staff want to see

At the end of each interview, participants were asked for suggestions for improving support for people who have limited or no English in healthcare.

Below is a list of recommendations from patients who experienced language barriers, their friends and family, and staff who supported them.

- **Implement an automatic alert system** – nearly every member of staff interviewed, and many patients told us they wanted an alert system that automatically flagged people who needed additional language support.
- **Make sure digital systems are consistent** – The difficulty of using multiple systems to record language needs was raised by many staff members, from clinicians to reception staff. Having different systems creates gaps where a patient's language information can get lost. Implementing a single, coherent system to record information and referrals that will work between services was suggested by many staff. This would reduce the time spent on administration and reduce gaps in systems where patients' language information can get lost.
- **Easier access to translated written resources** – staff told us they would like basic information leaflets and template letters available in languages other than English.
- **Ensure that healthcare staff take the initiative to ensure that communication needs are being met** – many people we heard from were unaware of the

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<sup>4</sup> <https://www.nhs.uk/publications/ethnic-inequalities-in-healthcare-a-rapid-evidence-review/>

language support available. Staff should proactively offer language support to people who may need it.

- **Ensure support is flexible and based on individual needs** – people told us that staff should have the flexibility and confidence to offer targeted support that works for each patient. Patients also wanted more choice of interpreters and for this choice to be discreet.
- **Consider cultural differences and dialects when offering support** – We heard from many people that interpreters speaking their dialect were unavailable, or staff were not aware that different languages and cultures have different dialects. Patients told us they would like staff to be more aware of dialects and cultural differences.
- **Offer NHS staff training on how best to work with interpreters and patients with language barriers** – Patients told us they felt staff should have the training to ensure respectful and kind attitudes towards people with language barriers. Staff told us they wanted more practical support on working with interpreters in appointments.
- **As well as training for interpreters** – people felt that interpreters should be familiar with medical terminology.

Ultimately, we heard that people want better access to interpretation services. Offering interpretation and translation is still not seen as routine, despite improving patient outcomes and experience.<sup>5</sup>

Many of these practical improvements are mentioned explicitly in the NHS England [guidance for commissioners](#). Our evidence shows that these best practice principles are not being followed by staff. Ensuring that services have a statutory duty to provide language support to those who need it, and coordinating delivery both within and between systems, will address the issues discussed in this report.

# Recommendations based on our evidence

We have set out three recommendations for Department of Health and Social Care, NHSE and leaders across Integrated Care Systems (ICS):

1. [Guidance for commissioning interpreting services](#) should go beyond commissioning and primary care. The guidance needs to be on a statutory footing for all healthcare services. Services must have a duty to ensure that interpreting services are provided when required.
2. A review of standards surrounding interpreting and translation should deal with all major areas for improvement identified in our [recommendations](#) for the review of the Accessible Information Standard. This should include

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<sup>5</sup> British Journal of General Practice: [Interpreters: why should the NHS provide them?](#)

improved frameworks for accountability, improvements in IT systems to support patient flags and sharing of information, involving patients in designing services and improving staff training.

3. Use the transition to Integrated Care Systems to clarify the duties of ICSs in the provision of interpreting and translation services, including considering how interpreting and translation services can best be delivered in a coordinated way through a single ICS-level contract where possible.

# Research methodology

## What we did

We grant funded six local Healthwatch who were able to reach people who speak little or no English:

- Healthwatch Camden
- Healthwatch Croydon
- Healthwatch Hackney
- Healthwatch Liverpool
- Healthwatch Norfolk
- Healthwatch Reading

They carried out one-to-one interviews with at least eight people. They also conducted separate focus groups with five to 10 members of a community who generally find it difficult to interact with healthcare services due to their limited English.

In addition, local Healthwatch interviewed at least five professionals working in a healthcare setting to understand people's experiences from their perspective.

## What local Healthwatch did

Local Healthwatch engaged with local organisations working closely with or supporting non-English speakers with various activities. Some even offered supermarket vouchers to participants to participate or a donation to the charities who organised the interviewees.

Local Healthwatch used different engagement methods depending on what worked best for the participants – they used face-to-face meetings, online calls and the telephone to carry out the interviews. To help with the discussions, they worked with professional interpreters or individuals working with the communities who also spoke the participants' languages. Some used Language Line, a telephone interpreting service for the telephone interviews.

They recruited staff members using their pre-existing contacts with local physicians, dentists, pharmacies and staff who work in a hospital setting. Some also recruited people who work in translation services.

Local Healthwatch carried out the interviews and the focus group discussions in October and November 2021.

## Working together

We worked with the six local Healthwatch and a panel of “experts by experience” from [Doctors of the World](#) to produce an interview guide. The guide ensured that the evidence collected during the interviews was comparable.

## Data collection and analysis

All research participants consented to the interviews. Local Healthwatch captured the discussion using live translation services or made notes and shared them with us via secured email accounts. Our researchers coded and analysed the discussion notes using dedicated qualitative analysis software.

# Our research participants

## Patients

We spoke to **109 people** who speak very little or no English. They either rely on their family members or professional interpreters to help them communicate. In some cases, they use their limited English to interact with healthcare providers. **Four family members** in this group were fluent in English and generally supported their relatives during healthcare appointments.

All our research participants belong to ethnic minority communities – nearly three quarters (74%) are from Asian and African heritages. The remaining 26% are from Europe and the Americas. The details of their ancestries are as follows:

- **Asia** – Arab, Bangladeshi, Chinese/Cantonese, Iranian, Iraqi, Kurdish, Nepalese/Gurkha, Pakistani, South Asian, Syrian, Tamilian, Turkish, Yemeni
- **Africa** – the Central Africa Republic, Eritrean, French-African, Somalian, South Sudanese, Zambian
- **Europe** – Greek-Cypriot, Latvian, Lithuanian, Polish, Portuguese, Roma, Romanian, Russian, Spanish, Ukrainian
- **Americas** – South American, Honduran

At least 67 participants (61%) identified themselves as a woman and 17 as a man (16%). The remaining participants did not share their gender information. Most participants were in their 40s to 70s; however, a few were in their 20s to 30s, and three were 80+ years old.

## Staff

We also spoke to **38 healthcare staff members**, including a few professional interpreters. The details of their roles are as follows:

- **Primary care** (10) – General Practitioner (GP), GP receptionist, NHS dentist
- **Hospital-based** (20) – Associate Director of Nursing, Head of Nursing (Surgery), Head of the patient experience, Head of Business Support, Central Booking Service Manager, Hospital booking staff, Senior Charge Nurse, A&E nurse, Ophthalmology nurse, Ward Manager, Physiotherapist, GP patient liaison officer, Speech and language therapist, Admin Team Lead for Pain Service, Patient Services and Resource Manager, Complaints Officer for NHS trust
- **Community-based** (three) – Community pharmacist, Community nurse, Midwife
- **Other** (five) – Occupational Therapist, Commissioning interpretation services, staff of the organisation that provides care packages to Chinese families, Arabic-speaking interpreter who works in hospitals, Practice Educator



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