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Accessible and inclusive communication within primary care:

What matters to people with diverse communication needs

June 2023

Background

Primary care services are the front door to the NHS – they are the first port of call when we feel unwell and the main coordinator of care when we are living with health conditions. The primary care team have an important role in making people feel welcomed, listened to and taken seriously.

Yet, at National Voices we often hear examples about people who have not had their communication needs met within primary care. This includes people with sensory impairments, people with learning disabilities, autistic people, people living with dementia, people who don't speak English fluently, people with low or no literacy, people who are digitally excluded, people who low health literacy, people living nomadically, people experiencing homelessness and many others.

As just one example, five years after the launch of the Accessible Information Standard, 67 per cent of Deaf people reported that still no accessible method of contacting their General Practice had been made available to them (Signhealth, 2021).

Project scope

At National Voices, we believe that in order to ensure equitable access to, experience of and outcomes from primary care services it's important that services are enabled and supported to meet the communication needs of the whole population. Through this insight and learning project we set out to understand:

What key issues patients with specific communication needs face within primary care and what they feel would make the biggest difference.

What barriers and challenges primary care teams experience in meeting diverse communication needs.

Where innovative and positive examples exist of inclusive and accessible communication approaches within primary care.

How these insights can inform communications with patients who are waiting for appointments/care in the current context.

The insights set out in this learning pack are drawn from a review of the literature and a number of engagement sessions with people with lived experience of communications challenges and organisations working with them, and with primary care professionals and professional bodies representing them.

Key definitions

For this project, we have used the following definitions:

Primary care services are the front door to the NHS. The term "primary care" encompasses General Practice, Dentistry, Pharmacy and Eye Health services. These services are the first port of call when people feel unwell and the main coordinator of care for people living with health conditions.

"Communication" encompasses the full range of interactions primary care team members have with the public – including letters, emails, texts and phone calls about appointments; websites; signs and other information provided in settings; interactions with staff, including health care professionals in clinical settings; and communications about primary care services for example on posters, on social media etc.

Context of pressures in primary care

We know that the experiences outlined within this report happen within the context of a primary care team under exceptional pressures – less GPs deliver higher numbers of appointments than ever before (BMA, 2023) and 68% of GPs say they don't have enough time to adequately assess and treat patients during appointments (RCGP, 2019).

It's important to note that when people attempt to access primary care and do not have their communication needs adequately met, there is a risk that they will either keep trying to access services through different routes – which leads to increased demand on health care services – or that they will stop trying altogether which can result in poorer health outcomes and inequalities for people with specific communication needs.

Relevant legislation and guidance

There is a wide range of legislation and guidance which reinforces the importance of meeting people's diverse communication needs and outline how to do this, for example:

- The Accessible Information Standard sets out a specific, consistent approach to meeting the communication needs of people with a disability, impairment or sensory loss.
- The Equality Act 2010 requires that an organisation that provides services to the public must not treat someone worse just because of one or more protected characteristics.
- The public sector equality duty requires public authorities to consider or think about how their policies or decisions affect people who are protected under the Equality Act.
- NHS England have published Guidance for commissioners: Interpreting and Translation Services in Primary Care.
- The Public Sector Bodies Accessibility Regulations 2018 requires websites and applications hosted by public sector bodies to meet minimum accessibility requirements.
- NHS England have published guidance on creating accessible websites e.g. for GP practices.

However, our engagement with people with diverse communication needs highlights that implementation is patchy across health and care. For example, recent research shows that only a third of NHS trusts that responded to a Freedom of Information request were fully compliant with the Accessible Information Standard (Healthwatch, 2022)

Who is affected?

While poor communication practice can create challenges for everyone, there are some groups who may be particularly likely to need tailored support around communications within primary care.

While meeting the needs of people with specific communication needs receives scant attention in policy discourse around health and care, a significant number of the people are affected. For example:

- Approximately 70,000 people in the UK are born profoundly deaf or become Deaf before they can speak (SignHealth)
- 340,000 people are registered blind or partially sighted in the UK (RNIB)
- 7.1 million adults in England can be described as having 'very poor literacy skills' (National Literacy Trust)
- There are 1.5 million people with a learning disability in the UK (Mencap)
- 863,000 people in England and Wales can not speak English well or at all (Office for National Statistics)
- 4.3 million people in the UK are unable to do any of the activities described in the five basic digital skills (Lloyds Bank)
- There are around 700,000 Autistic adults and children in the UK (National Autistic Society)

Why does communication matter?

The evidence demonstrates that poor communication is linked to:

- Lower patient satisfaction
- Reduced likelihood of receiving personalised care
- Reduced ability to participate in own care

See for example: https://pubmed.ncbi.nlm.nih.gov/35862510/

- Poor communication damages trust and can lead people to avoid seeking support, allowing problems to worsen
- Communication is the largest single reason for complaints against the NHS, across all groups in the population

See: https://digital.nhs.uk/data-and-information/publications/statistical/data-on-written-complaints-in-the-nhs/2020-21

Key Challenges

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Common challenges

Across our conversations with people who use health and care services and our review of the literature a number of communication challenges were identified across all groups. These include:

- **Inadequate record keeping** around communication needs, leading to people repeatedly receiving information in inaccessible formats, and having to advocate for the support they need at every contact.
- **Failure to make adjustments** that could benefit everyone who uses primary care: e.g. avoiding the use of jargon / medical terms without explanation; offering large print and easy read formats; using pictures and icons as well as words on signs and instructions; offering to write down instructions for people to refer to later.
- **Lack of continuity of care**, leaving people unable to build relationships, and having to repeatedly explain their needs, or leaving gaps in care which results in unmet and escalating needs.
- **Failure to treat people with communications needs with dignity and respect**, poor attitudes towards and assumptions about people with specific communication needs.
- A tendency in some instances to **talk over, or ignore** people with communication needs – speaking to carers or family members instead of the individual. A tendency in other instances to ignore or not listen to carers who often play an important role as advocates.

Other communication challenges which were identified across all groups include:

- **Inadequate appointment times** leading to insufficient time to ask questions and clarify information provided.
- **Poorly designed websites and applications** which make access more difficult for people with specific needs.
- **Lack of familiarity with how primary care is structured**, including which services are provided in which settings, and where to go for different kinds of support. These issues can particularly affect those who have recently migrated to England, and / or people who have complex needs.
- **Lack of support for self-care and self-management** among people with specific communication needs.

Specific communications challenges experienced by particular groups

In addition we heard of a number of specific challenges faced by particular groups. These include:

- For D/deaf people: Failure to meet communications – for example, failure to provide access to **BSL interpretation** for people reliant on BSL and assumptions that written communication is a substitute for interpretation (for many BSL users English is a second language). As another example, failure to **support lip reading** for people reliant on lip reading – by not communicating face-to-face, or using masks / communicating from behind barriers.
- For people who do not speak English fluently: Failure to provide access to **language interpretation**; often leading to reliance on family members to interpret, which in turn can lead to reluctance to disclose personal information vital to patient care. Failure to ensure effective interpreting, or in some cases **matching people with a translator who speaks the wrong dialect**. Often interpreters will interpret English jargon using the equivalent **jargon**, which in many cases doesn't help. Furthermore, for Roma, often interpreters have their own negative views about the communities and this impacts the quality of the service.
- For people with learning disabilities: Failure to offer access to **easy-read information.**
- For people with learning disabilities and some autistic people: Failure to **offer alternative communication channels for people who do not use words** to communicate.
- For people with dementia: Failure to **involve the person with dementia** – e.g. talking over them to a carer; a lack of support around memory (e.g. offering to write down new instructions, rather than assuming they will be remembered), failure to **speak clearly and slowly**, allowing time for responses, also lack of planning around carer involvement, advocacy and ability to consent.
- For people experiencing homelessness and those who live nomadically: **Refusal to register** or provide services to people without a fixed address / proof of address / identification, or communicating primarily by post to people with no fixed address. This is often also the case for people who live in precarious housing who can't procure proof of address or have landlords who do not allow use of the address.
- For people with low or no literacy: **Failure to provide verbal explanations for written information** or to support with form filling.
- For digitally-excluded people or people who prefer not to use digital services: **Lack of access to information and systems which are offered online** e.g. text message, especially where links are included; and **lack of choice** around online versus telephone or in-person appointments; online only appointment systems. For some, failure to use technology in a way that includes carers where appropriate.
- For people who have experienced educational inequalities: Failure to **explain information in a way that is understandable** e.g. using formal language, or medical jargon.

Things are getting harder…

We heard that recent changes, some linked to social distancing measures for COVID-19, but also more general shifts in primary care practice were worsening communication challenges faced by some people:

- Many **online consultation** systems were widely considered overly complex – with multiple questions – and were not accessible to people who were digitally excluded.
- GP practices / other services increasingly using **intercoms or entry phones** make buildings inaccessible to people who are D/deaf or who do not use words to communicate.
- Services using (often small print) **posters to explain new procedures**, which are not accessible to people with visual impairment or people with low literacy.
- Staff in pharmacies, dental practices, opticians and GP practices sitting **behind screens / wearing masks** which exclude people who lip read and can make it harder to hear.
- COVID-19 **backlogs** are increasing pressures on primary care teams' times, making it harder to get longer appointments.
- Increased challenges **ordering and receiving new and repeat prescriptions**, with poor communication about changes in prescription process.

Coping and working around...

Where primary care services fail to communicate appropriately, we heard that people often feel forced to find workarounds, often at significant cost and with implications for their health:

- People are often **forced to rely on family or friends** to interpret (into BSL, or other spoken languages) leading to a loss of dignity and privacy. This can mean people avoid discussing certain issues. This challenge is greater in some cultures – for example, it is often considered taboo for Roma women to discuss women's health in front of men.
- People end up **reliant on an individual member of staff** who is particularly skilled in communication, but miss out when that staff member is unavailable or leaves.
- Communities share informal tips around which services are good at meeting their communication needs, but this can lead to an **over-reliance on these services** – e.g. a GP may end up being asked questions more appropriate for a pharmacist, or dentist.
- People find ways of **circumventing processes** that don't work for them – e.g. finding which words on some online consultation form trigger a call back, rather than saying what they need.
- People lose trust in the NHS and **turn to private care or return to their country of origin for help**, at great cost and sometimes incurring debts.

Communication matters…

We heard stories of the impact of failure to support communication:

"Because she did not want to talk about personal issues in front of her son [who had been asked to step in to interpret] she did not explain where she was feeling pain. By the time her cancer was diagnosed it was too late for treatment."

Mihai, Roma Support Group

"Last year I had a problem with my eye, I bought some glasses at the optician, but they didn't help so the optician made a referral to the GP who then referred me on to the eye clinic. After a wait of five or six months, I was given a video appointment. I requested an interpreter, but when the call came there was no one on the line so the doctor closed the call. I was then given a face-to-face appointment, but had to wait another six months. Again no interpreter was provided, so the appointment was wasted. I received so many letters about this and I collected them and took them to my GP, but the GP said my case had been closed as I had not turned up to my appointments. All this time the pain in my eye continued. I still cannot see well from that eye."

Octav

"Because he doesn't use words to communicate, the move to the phone means he is cut out of conversations about his own health."

Learning Disability England member, regarding her son

Communication matters…

We heard stories of the impact of failure to support communication:

"My pharmacist is as helpful as they can be, they collect my prescription for me and give me any advice they can. However, if I have question about my medication, I prefer to make an appointment with my GP as he takes time to listen to my questions."

Gary, Learning Disability England

"What good is telling someone they have an appointment in two weeks' time if they don't have a phone or calendar to note the appointment down?"

Rachel, Groundswell

"My mental health suffered due to the strain of having to make a complaint, after I was refused a BSL interpreter for my appointment."

Anthony

"NHS 111 allows me to call using a live sign language interpreter service, but then they want to call me back and the link is lost."

Abigail, SignHealth

"Sometimes the doctor will print off an easy read leaflet, but the letters that come from the surgery are not accessible, and I have to ask for help to understand them."

Anthony

Breakdowns in communication

Trust was a key theme across all groups. Where communication is poor and people are not well served by primary care services, this can lead to a breakdown in trust – this in turn can lead people to avoid accessing services, either leaving health needs unchecked, or accessing inappropriate services such as A&E.

What does **good communication** look like?

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What does good communication look like?

Good communication is defined by:

- **A personalised approach** – with communication styles and techniques tailored to individual needs.
- **Flexibility** – offering people a range of different ways of communicating, including options to communicate without using words (e.g. using pictures).
- **A positive attitude –** Listening empathetically and respectfully.
- **Understanding** – Checking that people you've understood what people want, and that information has been understood, for example by inviting questions and encouraging people to repeat back what they have heard.
- **Building trust** – Giving people enough time and space to express themselves, and taking time to get to know people and forge relationships.

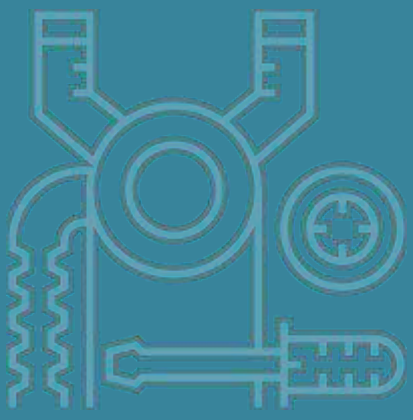
Some of the key ways we can ensure good communication, include:

- **Avoiding assumptions**.
- **Using trauma-informed approaches** and interpreting behaviours through a lens of understanding trauma and the impact of stigma.
- Offering **culturally appropriate support** including avoiding assumptions about diet, lifestyle etc.
- Offering **consistency and continuity** – so people do not have to repeat their needs or advocate support at every contact.
- Being **proactive** in offering support rather than waiting to be asked.
- **Avoiding infantilising adults** with specific communication needs.

What needs to happen to enable this?

The key priorities for action include:

- **Ensuring communication needs are consistently recorded and flagged** at all key points along the pathway, and ensure interoperability of systems to support data-sharing across different primary care providers and staff.
- **Improving all general communications** – making sure that all communications are optimised for accessibility – for example through the routine use of plain English, accessible fonts and larger print sizes, use of pictures and symbols alongside words, and auditory as well as written communication of key information so that as many people as possible can access communications without the need for specific adjustments.
- **Meeting legal requirements** around inclusive communication – under the Accessible Information Standard and the Equality Act.
- **Training the primary care workforce** – ensuring that all staff in primary care, including reception and administrative staff as well as those in clinical roles have access to high quality training on inclusive communication, ideally involving people with lived experience of communication challenges. This should be routinely included in initial training and also part of continuing professional development.
- Ensuring more **consistent access to sources of support** in the community (for example community advocates and community health mediators), with a focus on what matters most to the person accessing care. This includes in investing in and developing strong partnerships between voluntary and community organisations, and the NHS.



What could **we build** on?

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VCSE sector support

Tapping into existing resources and capabilities in the VCSE sector to support people with additional needs to access primary care will be vital, but at present awareness of these services is patchy. Examples of these include:

- SeeAbility which offers resources to optometry services for people with learning disabilities.
- Easy Health which offers free downloadable Easy Read format resources on a wide range of health conditions.
- Groundswell's My right to healthcare cards which help people experiencing homelessness or living nomadically assert their right to access healthcare without formal identification or a fixed address.
- Many more local and national organisations that support people with different conditions around **self-advocacy** and access to health. In some places these are co-located with primary care providers, to facilitate easier access.

Examples of positive practice

We also identified examples of positive practice during the pandemic, that could provide models for future action. These include:

- SignHealth's BSL Health Access programme which was available during the COVID-19 pandemic to provide free access to BSL interpretation via video call 24 hours a day.
- Vaccination centres which were set up during the pandemic specifically for people with learning disabilities and autism to provide an environment with fewer distractions and more time for each patient.
- We also found examples of primary care leaders working in coproduction to create accessible communications resources, for example:
- The General Dental Council has coproduced a poster and leaflet outlining best practice in complaint handling.

What would make **a difference?**

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Proposed actions

Based on the insights gathered we propose that NHS England should develop a programme of work to support Integrated Care Systems to work with their local primary care providers and people with lived experience of communication to codesign, coproduce, and implement actions to support inclusive communication.

01

For NHS England to work with professional bodies and patients to improve training for primary care staff: Coproduce training modules for primary care staff with people with lived experience of communication issues. This should be provided to all administrative and front-of-house staff as well as clinicians. This training should also include a focus on communication that is meaningful with a person focused understanding of needs.

02

To ensure people do not have to fight to access communication support: Integrated Care Systems should appoint a named champion at place level to lead on inclusive communications.

03

To improve the flagging of communication needs on NHS primary care records: people with lived experience of communication issues should work with NHS digital bodies to review how digital tools could be better used to support the flagging of communication needs, paying attention to the prominence of flags as well as the information recorded; ensuring these are interoperable with automated systems (e.g. for letters and texts); and ensuring that systems support appropriate data sharing across care providers.

04

To make best use of available assets: NHS England should work with ICSs to develop resources and support to strengthen links between primary care providers and community-based organisations to improve access to support around communication, in particular, through bi-lingual community advocates and community health mediators.

05

To ensure communications are fit for purpose: Integrated Care Systems working with primary care providers, patients and communities should codesign and coproduce new tools (guidance, resources etc) to support communication with people with diverse needs – these should cover general communications (e.g. posters to advertise services) as well as tailored personal communications and protocols for within consultations.

Proposed actions

06

To ensure that providers are encouraged to meet access needs: NHS England should provide guidance for commissioners to ensure they have the tools they need to commission for access and inclusion in primary care, this should include updated guidance on commissioning communication support (e.g. translation) as well as around ensuring providers are committed to inclusive communication.

07

To make it easier for people to understand how to access support: NHS England should work in coproduction to create standard procedures across health and care for common communication support requests – including, as a minimum, requests for interpreters, longer-appointments, easy-read information, braille letters etc., no telephone calls / no letters etc – with appropriate resourcing to support their implementation.

08

To support people in asserting their needs and rights: NHS England should work with people with lived experience to develop simple tools to support people in communicating their rights to communication support – building on the example of Groundswell's "My right to healthcare" cards.

09

To strengthen understanding of legal responsibilities around communications: NHS England should share lessons from the recent review of the Accessible Information Standard with primary care teams across England, and communicate widely when the new Accessible Information Standard Specification and Implementation Guidance is published.

10

To strengthen accountability for services who fail to meet communication needs: The Care Quality Commission should review and strengthen their approach to regulating primary care services, giving greater prominence to understanding whether services have effective processes in place to meet the communication needs of diverse groups of people.

Primary Care Recovery Plan

A number of the activities outlined in the May 2023 NHS England Primary Care Recovery Plan provide opportunities to strengthen knowledge and action within primary care services in meeting diverse communications needs.

- We propose that national and local support to implement 'Modern General Practice Access' through better digital telephony, simpler online requests, improvement support and investment in care navigation should have a specific focus on better meeting diverse communication needs.
- We propose that NHS England's proposed work to improve the primary-secondary care interface should consider how services can more effectively ensure people's diverse communications needs are communicated and met at the point of referral.
- ICSs are asked to implement the guidance on highly usable and accessible GP websites for patients. We propose the development of national and ICS led communications and materials to support practices to better meet the diverse communication needs of the people they serve.

Overview of key issues and recommendations

Key issues	Proposed Actions
Many primary care staff don't feel confident in meeting diverse communication needs.	1. Strengthen training on inclusive communications for primary care staff. 2. Create new tools and guidance to support communication with people with diverse needs. 3. Share lessons and next steps from the recent review of the Accessible Information Standard with primary care teams across England. 4. Create standard procedures across health and care for common communication support requests.
People with specific communication needs don't always know what their rights are or feel confident exercising them.	1. Develop simple tools to support people in communicating their rights to communication support.
Digital systems, which could be used to record communication needs, are often underutilised or incompatible with systems used in other parts of health and care.	1. Strengthen use of digital tools to flag communication needs. 2. Including a focus on better meeting diverse communication needs within activities on improving the primary-secondary care interface.
Accountability and leadership on the need to meet diverse communication needs within primary care are often weak.	1. Appoint inclusive communications champions in every ICS. 2. Review and strengthen regulation of primary care services, giving greater prominence to services meeting diverse communication needs.
Commissioning of primary care services often doesn't take into account the resource needed to support diverse communication needs, the importance of this or how to do it well.	1. Create guidance for commissioners on supporting inclusive communication in primary care. 2. Strengthen links between primary care providers and community-based organisations to improve access to support around communication.

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National Voices

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

We make what matters to people matter in health and care.

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