



Unlocking the digital front door: a call to action

Insight report and call to action from projects in 2020-2021.

Conversations about inclusive healthcare

We have been reflecting on the last 18 months, and think it's a good time to share our thoughts and observations about the rapid shift to digital healthcare and its impact on people who are at risk of digital exclusion.

At National Voices we are in a fortunate position as we have regular contact with community groups, people who use services, thought leaders from across the Voluntary, Community and Social Enterprise (VCSE) sector, health and social care system and policy leaders, commissioners, and providers. We have conversations every week about the challenges they face and planned improvements, we read and often support the research and contribute to debates about policy and practice.

This year, more than any, we have had the opportunity to listen to people's experiences, both via our own projects and that of our members and partners. **There is much to celebrate about the NHS response to COVID-19 and we know how hard our friends and colleagues across the health and care system have been working.** We are also conscious that some have paid the ultimate price for this dedication and many may still suffer with the long term consequences of having contracted Covid at work.

We have collated and are now [sharing innovations](#) that have been delivered by our VCSE colleagues and we are excited by the messages these examples send about the possibility for change. **The community and voluntary sector is well placed to innovate effectively, and puts time and effort into relationship, skill and confidence building through peer support.** In a crisis, they have been able to reach out to vulnerable communities, with different needs and find workable solutions at pace.

However, innovations and solutions that have been developed in response to a crisis will need ongoing support. As we move towards national recovery, we will need to build new models of partnerships and funding.

Community innovations also cannot compensate for exclusive or badly designed services. We need to both design for inclusion and build partnerships for outreach and support. The [stories of digital healthcare](#) we have heard directly from people who are at risk of exclusion paint a sometimes worrying picture of people finding it difficult to get the help they need in a way that creates both value for them and the system. People have differing needs, safety concerns, access requirements, anxieties, cultural considerations – and ignoring this context risks shutting people out.

We want services to focus on offering supported choice and personalisation. **It is clear to us that we need to bring together our understanding of inequalities, digital transformation and personalisation** if we want care to provide inclusive access, a good experience and equitable outcomes for all people.

This paper lands at a critical time for health and care, with particularly primary care colleagues feeling overwhelmed, whilst at the same time people report difficulties to access care. We intend our intervention to be a conversation starter. Clearly, we can't solve this problem on our own. But neither can the NHS. Do reach out if you want to build practical solutions for inclusive, equitable and personalised care.

What we have done

Much of our work with members during COVID-19 has centred around health inequalities and supporting those with the most need. During the first lockdown we launched [Our Covid Voices](#) to collect and share the experiences of people with long term conditions, we hosted a [series of webinars](#) that attracted more than 600 people from over 400 organisations.

Our work on the [experience of waiting for care](#) has shown us how abandoned some people have felt when services were disrupted and cancelled, but also that it is possible to ensure people still feel seen and heard.

We worked with Traverse and Healthwatch on a rapid, qualitative insight study [The Doctor Will Zoom You Now](#), designed to understand the patient experience of remote and virtual consultations.

Throughout we have drawn on the insight and input from members of National Voices who worked with us to better understand such experiences and what could be done to improve them.

We have brought our insight together into a set of [new I statements](#) that set out clearly what people say they need now. Our work has influenced guidance to the NHS and been referenced widely.

To understand the perspective of people attempting to use services we have worked with partners to carry out a [listening exercise](#) with people at risk of exclusion about their experiences of accessing healthcare.

We have pulled together an [inspiring list of interventions](#), innovations and initiatives that describe VCSE activities, often in partnership with statutory services, to enable digital participation and inclusive remote support.

We have worked with the Patient Experience Library and Care Opinion to understand the [available evidence about digital exclusion](#).

We supported Ipsos Mori with as yet unpublished work on access, and worked with Oxford University and the Nuffield to better understand how digital transformation is shaping primary care now.

In March we hosted a [flagship conference](#) on different aspects of health inequity, funded and supported by the Health Foundation and PPL, where we made a commitment to build on the insight and energy created and to codesign a coalition for action on health inequality, including digital exclusion.

Based on all this learning, we have developed [recommendations for practice and policy](#). We also decided we needed some information that explains to people themselves what they can expect when using health services. We are pleased to report that this information has been endorsed by the RCGP and RCP and by many of our members.

This information can be printed off and used as a poster or leaflet. We are hoping it will be widely used.

Listening to people: What is going on? What can be done?

We wanted to fully understand the barriers to good care, particularly from the perspective of people at risk of exclusion, with high burdens of ill health and who are affected by inequality.

Our [literature review](#) showed that there was a clear technology optimism bias in the existing literature, with confident predictions about the improvements that will happen on the back of technological transformation, and scant attention given to the actual experiences of patients or even staff.

So we worked with the Abbey Centre in central London, the Centre for Seldom Heard Voices and Change People to interview people who could help us understand what was happening and what needed to be done. You can read their thoughts [here](#).

Through our listening exercises we have identified the following themes:

- People understand the reason for and potential benefits of remote care.
- Many people have struggled to access services during COVID-19.
- People might be digitally excluded for a range of reasons.
- People present with a range of support needs; one size does not fit all.
- Poorly executed remote care impacts on experience and quality of care.

Digital exclusion contributes to the inverse care law; it plays out against the backdrop of existing inequalities. We need to make conscious efforts to prioritise inclusion, equality and personalisation. One size does not fit all, and without listening and responding to people's experience, we lock people with more difficult lives out of the care they need.

"I could not complete an online form, I couldn't do it, I wouldn't know how to access the app in the first place or how to put an app on an iPad, I wouldn't know where to start. I seem to get in a muddle but if I had to do something out the ordinary ie access and fill in an online form, I wouldn't be able to do it."

"When I phone to speak to GP, receptionist ask what the reason and she explains. Then she says the Dr will call you back. I do not know when the GP will call back. Later, when the Dr phone called, some of the things I forgot. I cannot explain properly. It is very difficult."

"Then I have a phone conversation with another doctor, and I just said, "listen I am quite emotional, quite unwell right now, I need to see someone face-to-face, sometimes I am not very good over the phone."

"It's unfair if everything's 100% on computers, it's totally unfair."

Better understanding of digital exclusion: Who is excluded and why?

We understand that people might be digitally excluded for a range of reasons¹.

People's experience is not shaped by one aspect of their identity alone but by a combination of health and social elements that might include: ethnicity, gender, age, religion, class, financial situation, or location.

Often people have more than one reason why they might be at a disadvantage. People might face barriers to digital health if they are disabled, blind or partially sighted, deaf, have dementia, learning difficulties or mental health issues. People who are facing homelessness, Gypsy, Roma and Traveller communities, migrants, refugees, and asylum seekers, and those needing translators/interpreters may also face challenges.

Skills: People might have limited experience of technology. Low literacy also often goes hand in hand with low health literacy, and low digital literacy. We also know that these specific exclusionary effects interact with and are overlaid by wider dimensions of exclusion, such as language barriers.

Access, including Poverty: Many people have no, or very poor Wi-Fi. Some people don't have access to regular charging facilities. Many require supportive aids or translators. People might not have access to or be able to afford a phone or computer. In addition, they might struggle to pay for data.

Confidence, Safety and Trust: People may be nervous because virtual healthcare is new, or because there are cultural or other personal barriers. They might lack a private space. People might be worried about and have low levels of trust in the health system generally, as well as in virtual healthcare. People might have questions about data protection and management. People might not have a safe place for virtual health, communication might be compromised.

"My in-laws are deaf and recently, they've felt cut off, largely because everything became telephone based and for people who can't hear on the phone, that's difficult."

"English is not my first language so if you make just one mistake with an online appointment then everything is not going to work for me... it is so difficult."

"I was in tears so he phoned the doctor but there are things I would not talk about in front of my husband, I've always been independent, totally private about myself so there is a risk."

The Case for Change

COVID-19 has necessitated a rapid move to virtual healthcare. In some cases, this move to remote access has been welcomed. Technology can be a real enabler of better engagement and inclusion - people attending a peer-support group for the first time or adapting messages on WhatsApp to reach people who don't speak English as a first language. There is a moment now, to build on these positives and learn from them.

However, in many cases this shift has brought about even more barriers to getting good care. There are a number of reasons why people might be digitally excluded, and we know that if we exclude people digitally, we are contributing the inverse care law: people with higher burdens of ill health are already less well served by the existing models of care.

We know from listening to people that when virtual health care is poorly executed quality of care suffers. We have found that people are sometimes locked out of a decision about how they access care, even before the idea of a virtual appointment is suggested.

For too long, system leaders have focused on specific technologies or set targets for the ratio of digital or face to face services or for hours to open surgeries and so on. We need to focus much more on the outcomes we need to achieve: equitable and inclusive access for all, and particular for those people at the wrong end of the inverse care law.



Insight for better practice – Recommendations for people working in health services

- **Communicate clearly and without qualifications that you want everyone to have access to your care.**
- **Focus on quality and equality in everything you do.**
- **Offer supported choice and personalisation.**
- **Seek feedback and focus on improvement as a result.**
- **Coproduce solutions with people, collectively and individually.**
- Consider your website, answer machine message, emails and texts – what impression do they create?
- Set out how you can adapt your service offer to meet people's differing needs: online forms, phone call, face to face – they are all just tools for inclusion and personalisation, none of them are 'right' or 'wrong'.
- Insist that all technology, platforms, and processes are properly user tested, focusing on those at the wrong end of the inverse care law.
- Give people a time window during which you will call them. People need privacy and focus to help co-create high quality health care.
- Refresh and strengthen your commitment to the Accessible Information Standard.
- Provide training to both staff and users about new processes. Acknowledge that change isn't easy and respond to frustrations.
- Design services with a deep understanding of the needs and preferences of people, particularly those at risk of exclusion and with the highest care needs.



Insight for better policy – recommendations for system leaders

- **Make inclusion the core principle driving your work on recovery and restart.**
- **Ensure that choice and personalisation are the formative design principles for all care, and for primary care in particular.**
- Check your technology optimism bias: do not incentivize the use of certain tech or processes – only incentivize inclusion and quality care.
- Evaluate and publish how your transformation programmes impact people at risk of exclusion. Set out what you are doing to mitigate these risks.
- Publish your results of user testing and set out plans on how you will improve people’s experience.
- Invest in technology that clearly demonstrates how it aids inclusion.
- Understand, support and challenge primary care as the most important gate keeper and enabler of inclusive care throughout the whole system.
- Understand that health care is just one of the needs people have who are affected by poverty, racism or discrimination, build care models that allow for other needs to be identified and addressed appropriately.
- Secure funding that enables remote care to be delivered free at the point of use: free wifi, free data, free calls, free kit for those in need. It is not the job of the poorest citizens to subsidise the roll out of new care models.
- Refresh and strengthen your commitment to the Accessible Information Standard and Guidance on Communicating With Patients Who Are Waiting For Care. Provide funding for providers to ensure good communications.

Insight for better innovation

[Our work with the AAC](#) revealed how the pandemic created an environment where new partnerships, innovation and creative solutions could flourish. We need to nurture and grow this culture. **From this work, we have developed five recommendations for inclusive innovation:**



Make inclusion the core principle.

Offer the same levels of access, consistent advice, and outcomes of care to everyone, regardless of channel. One size does not fit all.



Co-design with people.

No matter how urgently new systems needed to be implemented, access requirements need consideration. Focus on people who are at risk of exclusion.



Offer supported choice and personalisation.

Adapt communications, offer different formats so that people could access care and information in a way that works for them. Listen to what they say.



Support staff to innovate.

Build a positive culture around testing new ways of working, put training in place and embrace and learn from feedback.







Know that health is wider than healthcare.

Many successful projects provided services and activities that were wider than healthcare to engage and support people, and through this, people were better able to self-care or access services.

Insight for empowerment – Patient facing information.

We have worked with our members and people at risk of digital exclusion to develop patient facing information on remote care.

Printable versions are available [here](#). Please feel free to use this in your services and share widely.

NHS APPOINTMENTS AND REMOTE CARE

KNOWING YOUR CHOICES




During this pandemic, staff have been working very hard as the NHS has been even busier than usual. Services are using different types of remote appointments, such as phone calls and apps. This is to keep patients, carers, and health professionals safe from coronavirus by reducing face-to-face contact.

Remote appointments work well for some people. Others may need services face-to-face because of: privacy; digital skills and confidence; access to connection, data or devices; concerns around cost; confidence reading, writing or using English, and specific communication requirements.

YOU CAN EXPECT TO:














- **Be seen in person** if that is the only way you can get good care – whether it is for a physical or mental health problem.
- **Get support from a staff member** to help you book an appointment.
- **Be able to request face-to-face support** if you cannot access the care you need over the phone or online.
- **Keep your information private**, and only discuss your health problem with a doctor or nurse.
- **Receive the same quality of care** as people who access health and care services online.
- **Have access to an interpreter** – this includes a Sign Language interpreter.














If you are booking an appointment for someone you care for, the same applies – **they can expect to access services in the way that best suits them.**

If you need a face to face appointment and are struggling to get one, you can:

- Explain to clinical or administrative staff that certain times or platforms do not work for you.
- Get involved in your local Patient Participation Group – healthcare staff can provide you with details.
- Say if something does not make sense or you do not understand. You can expect information in a language and format that works for you.
- Reach out to a charity that can support you – use www.mypickle.org to find out who can help.
- Contact your local Healthwatch who provide feedback to services.
- Provide feedback or make a formal complaint to the service.

Insight for inclusive, equitable, personalised and responsive care

What we conclude from what we heard?

Inclusion first needs to be the only principle guiding service transformation, not commitment to any particular channel or technology.

Not responding to people's stated needs leads to very poor-quality care.

People understand that there are benefits to digital, but need time, support, and resources to change and adapt. People who work in the system also need time to adjust, learn, build skills and confidence.

When people contact health services, they are often worried about something, they need a warm and welcoming experience of care. When we make things difficult, we are contributing to the inverse care law, because only the confident, capable, and demanding will get through.

People need informed and supported choice first, digital second.

Effective digital inclusion works best:

- When co-designed with people who use services.
- At the boundary between informal and formal support, with support by peers and advocates.

The community and voluntary sector is well placed to innovate effectively, but it needs to be engaged through strong partnerships and sustained investment to maintain and grow this activity.

Some of the changes we are proposing will require centrally sourced and sustained investment; all of it will require local, and tailored leadership, including from the Voluntary Community Social Enterprise sector.

More learning: Further need for better insight

We have (with very little resource) generated much insight and momentum for change. But there are questions we think merit further attention. We hope those with more resource will agree that these questions need to be answered urgently.

What informs a person's decision to reach out to health services for help, or not? Which beliefs and experiences underpin our expectation that we *deserve* care, particularly if we are less literate, less well off, or have experienced stigma or discrimination?

What communication approaches explain well how healthcare can and should be accessed, without putting off those who are least confident in their right to access care?

How can we more effectively support services, such as primary care with their communication to patients, their websites, texts, answer machine messages and so on?

Triage (online, telephone, face to face) is here to stay, and if done right could aid quality care, including equality and inclusion. So **what is a good user experience of triage?** How can online triage systems be improved? How can we make 'triage by receptionist' safe and inclusive?

What is the role of non clinical and front of house staff in enabling access and ensuring a good, inclusive experience of care? What works for supporting and challenging these staff groups to focus on access, inclusion and kindness?

How do personalisation and inclusion connect? What **flexibility** does staff at the point of care need to enable positive, inclusive responses to the many different circumstances people can find themselves in?

How can we embed healthcare in a network of relationships with community and voluntary action that taken together can hold people and their needs appropriately, focusing on the assets, strengths and aspirations particularly of marginalised communities?

Our call for action

We have spent the last 12 months working with our members who support people with their health and care needs and listening directly to people at risk of exclusion. We have insight into what has happened, what needs to happen, and also have identified further questions that we believe still need to be addressed.

We stand ready to work with our system and sector partners to bring our collective insight and ambition to the challenge of making healthcare access inclusive, equitable and compassionate, combining digital, face to face, and phone support in personalised ways.

We want to work with leaders nationally on:

- A holistic review of access to primary care in particular. The whole front door to the NHS has changed and is changing. We need to look at this issue in the round and place the needs of people for more equitable and compassionate care front and centre in plans for recovery.
- Clearer communications for how people are expected and supported to access the care they need.
- How local service leaders and providers can be better supported to design, and then explain service changes and access to the people they work for.

We want to help coproduce solutions for communication, triage, shared decisions and a better overall experience of care.

The last year has been exceptionally difficult for both staff working in the health and care system and for the people who need to rely on it. We believe that together, we can build on all the learning that has happened and create better, more equitable health for more resilient and engaged communities. We are here to help.

We want to work with partners towards a more joined-up, person-centred, safer, experience of care, where virtual and face to face services adapt to meet the full range of clinical, emotional and practical needs of people at risk of exclusion and address the barriers to access and use confronting some groups.

“It makes things worse for you if you do not have someone that is warm and supportive or for physical health if someone really knows how to engage with that person. It is more about the human kind of engagement.”

Thank you

The innovation report reference here was commissioned by the Patient and Public Involvement Team within the Accelerated Access Collaborative, NHS England and NHS Improvement. Thank you to Alice Williams and Nathalie Carter, for all your support. It was managed by Sam Hudson from Überology. As always it has been an absolute pleasure to work with her. National Voices colleagues have been great throughout, in particular Savannah Fishel who supported this work on all fronts.

The Abbey Centre in Westminster, the Centre for Seldom Heard Voices in Bournemouth, Change People and the Patient Experience Library were committed, and effective research partners. We will be back.

We designed and delivered this work through a project group consisting of a number of our engaged and expert members. National Voices would be nothing without them. Two of them, Diabetes UK, and Macmillan Cancer Support, also supported this work financially – for which we thank you.

We have benefited from working with Ipsos Mori and Healthwatch England, plus a number of great local Healthwatch organisations on understanding people's access needs. Thank you for your support and generosity.

Many more members and other community partners shared their innovations and ideas with us. We can't do justice to all of it – but the world is a better place because of all the good work they do.

Finally, people with often difficult lives agreed to being interviewed. Their insight and hopes drive our work. We are so grateful.


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National Voices is the leading coalition of health and social care charities in England. We have more than 170 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.

Do get in touch:

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