

We know what people want, but are we listening? Insights into patient voices on digital access to healthcare

Mel Hughes, Stevie Corbin-Clarke, Peter Greensmith

Dr Mel Hughes is Associate Professor in social work and Deputy Director of the Research Centre for Seldom Heard Voices at Bournemouth University

Stevie Corbin-Clarke, is a Research Assistant based within the National Centre for Post Qualifying Social Work and Research Centre for Seldom Heard Voices at Bournemouth University

Peter Greensmith is Chair of NHS England South West Transformation Patient Reference Group and previous Chair of Weymouth & Portland Patient Participation Groups (PPGs)

The Covid-19 pandemic prompted changes in the ways that individuals access healthcare services and accelerated the transition to digital methods of care. For some, this opened doors for easier and more convenient access. For people already experiencing exclusion and marginalisation however, digital access can create additional barriers for accessing healthcare. NHS Digital (2019) identified several groups as more likely to be digitally excluded:

- older people
- people in lower income groups
- people without a job
- people in social housing
- people with disabilities
- people with fewer educational qualifications, who were excluded from school or who left school before the age of sixteen
- people living in rural areas
- homeless people
- people whose first language is not English

The increasing digital divide between those with digital access and skills and those without (Local Government Association 2021) means that people from marginalised and excluded communities are disproportionately affected when seeking access to high quality healthcare (see Marmot 2021 for evidence of growing inequalities). Digital inequalities have been consistently shown to reflect deeper societal inequalities. Holmes and Burgess from the University of Cambridge Centre for Housing and Planning Research argue that *'The link between poverty and digital exclusion is clear: if you are poor, you have less chance of being online'* (Holmes and Burgess 2021).

In this article we share key findings from work undertaken in the rural and coastal county of Dorset on digital exclusion and inclusion to healthcare. We report on a doorstep survey conducted by a Patient Participation Group (PPG) of residents of Weymouth and Portland in West Dorset and of insight work conducted for National Voices by the Bournemouth University Research Centre for Seldom Heard Voices. West Dorset has high levels of deprivation, with 11 areas in Dorset being the most deprived in the UK (falling within the top 20% nationally) and with Weymouth in particular having the busiest food bank in the county. There is an ageing population in Weymouth and

Portland, which contributes to an increasing workload for GP practices and increasing medical complexity of patients in the area (Stead 2021, Dorset Community Foundation 2018).

The collaboration between Bournemouth University (BU) and the Weymouth and Portland PPG, sought to amplify patient voices and perspectives of digital access and to ensure that lived experience expertise informed service development. Whilst we anticipated issues relating to digital poverty (lack of access to the required technology) and technical expertise (not knowing or feeling confident to use the technology required) our findings suggest a more complex and nuanced picture. Barriers to digital access also relate to concerns about privacy and confidentiality, autonomy, and dependence on others; and feeling valued and included. It is essential that these views and experiences are understood and used to inform how healthcare can be accessed in ways which promote both choice and flexibility.

In November 2020, eight months after the start of the first lockdown, Weymouth and Portland GP Patient Participation Group (PPG) conducted a patient experience survey which resulted in 1891 responses (Dorset CCG 2021). 24% of respondents were not connected to or did not use the internet. This increased to 35% for those with a disability and 50% for those aged over 70 years. This was at a time during pandemic restrictions when almost all healthcare was accessed online or by phone. The lack of internet access reflects a 2018 Age UK study which found that 56% of people age 75+ had not used the internet recently and 36% (4.2 million) people age 65+ were offline: lapsed or never users (Age UK 2018). Whilst the ONS report in 2020 that 96% of households in Britain have an internet connection, this percentage reduces to 80% for those aged over 65 years (ONS 2020). In the PPG's Weymouth and Dorset survey, 76% of respondents had not accessed e-consult; 38% had not visited a health service website; and 40% had visited a health service website but infrequently. 20% of respondents reported not feeling confident with telephone consultations. 21% of patients felt they could not explain symptoms over the phone. This is reinforced by a report from Cambridge University which found that 86% of patients and 93% of clinicians thought that remote consultations were worse than face to face for accuracy of assessments and concluded that digitalisation and tele medicine should stay, but appropriate patient selection was important (Sloane et al. 2021). These findings raise significant concerns regarding access to quality healthcare for those with limited digital connectivity and skills and the impact it is having on those already disproportionately affected by health inequalities including older and disabled people.

As part of the Unlocking the digital front door report, National Voices, a coalition of 180 health and social care charities, commissioned Bournemouth University Centre for Seldom Heard Voices to collaborate with people at risk of health inequalities to create a series of insight narratives. The aim was to illustrate how digital measures being introduced by NHS England could impact those at risk of exclusion and what could help them to maintain their access to quality care.

Contact was made with community organisations that supported people from at risk of exclusion and semi-structured interviews were conducted by phone or in person so as to avoid digital barriers. Potential participants were sensitively sampled, to illustrate a range of voices and experiences. Participants consented to being audio recorded and to having their own words quoted anonymously in the insight narratives. Narratives include a variety of experiences, including being homeless, deaf and hearing impaired, visually impaired, older, disabled, with a long-term health condition and experience as cancer patients. We created 11 narrative insights documenting recent experiences of

accessing healthcare. Full narratives can be accessed at:

<https://www.nationalvoices.org.uk/publications/our-publications/unlocking-digital-front-door-keys-inclusive-healthcare>

Digital poverty and technical expertise

Several participants reported experiencing digital poverty, lacking the funds for consistent access to equipment such as smart phones or computers or to adequate data, with one of the participants only having access to a landline. This had prevented them from being able to send pictures or emails to their doctor when requested to do so. For others, poor internet access and phone signal had prevented them from seeking the medical help that they needed, such as lack of signal in more remote areas. Helen explained that in her village she knows of at least *'two or three people who, if they need to make an emergency call, they haven't got a landline and have to walk to the bottom of the garden to get a signal'*. This has significant implications for patients wishing to discuss confidential issues with a health practitioner.

As to be expected following the Age UK report and the PPG's doorstep survey, age was a factor when considering digital poverty and technical expertise. Maria said she felt that older people are *'from an age where you didn't even have a calculator at school, houses didn't have telephones, and this is what we're stuck in and we've been around so long that our brains are overloaded and don't want any more technology'*. This went beyond lack of access and digital poverty. Carol shared *'I'm not online at all, my grandson offered to buy me a computer, but I said "no, thank you", money wasn't the problem, it was me'*. For some, not being online is simply a choice.

Some of the participants were new to using digital technology having lived a life without this level of use. They reflected on how they had tried hard to learn how to use technology; had attended computer courses; and had struggled to find websites they were looking for. Pam said she struggled to even turn on or login to a device and Maria explained that she will often tell her friends *'to go on an app'* and they reply with *'what's an app?'*

Concerns regarding using digital technology were not though restricted to the older participants. Simon describes himself as *'an addict'*, who has turned his life around and been in recovery since April 2020. He was previously homeless and extremely isolated from society by his drug use until he accessed a charity, who supported him into accommodation. Simon described several challenges he faces to be part of mainstream society. Technology greatly unsettled him, *'it hurts your head'*. He said that he doesn't feel comfortable in becoming dependent on technology. He had been given a tablet by a charity but was worried he wouldn't be able to afford to keep using it. His worry regarding the nature of access to equipment, data and adequate funds is a feature of digital poverty that is not always considered.

Quality of the interaction

The acknowledgment of multi-layered barriers as illustrated by Simon was a strong theme. Simon said that he used to have in-person one to ones with his doctor and discussed how he did not feel he would have survived without them. He fears that those who do not have easy access to in-person appointments with their doctor will suffer *'unless you see the person, there might be other things going on with them that they wouldn't picked up on themselves'*.

Another participant, Lisa, shared her concerns around not being able to have conversations about personal healthcare information privately and how this may discourage people from reaching out, particularly when you don't know what time the surgery will call you back: *'the first time I had a phone call like that I had to run away from someone to have it privately and... saying all those symptoms out in the middle of the street or on the bus, you're not going to'*. Lisa further explored this concern, as a domestic abuse survivor: *'I know if you don't document everything, each time you get hurt etc it's not viable in court, but I think some of that won't get documented anymore because they can't say it at home or in front of children'*.

Privacy and confidentiality and Autonomy and dependence on others

Those with both access to technology and the skills to use it, raised concerns about the lack of choice and flexibility over when to use different platforms and for what. Privacy issues were repeatedly discussed by participants either by having to have someone else involved; speaking in a public place; or in terms of sending personal images to doctors online or through messaging services. Patients we spoke with did not feel confident about the security of the images and who could end up seeing them. Paul has had Type 2 diabetes for 18 years and is visually impaired, with an ongoing melanoma in his right eye. He has also been a carer for his father who had liver and lung cancer. With all of these medical needs and responsibilities, Paul has struggled with the move to digital methods and is often unable to access digital forms by himself. He describes experiencing a loss of independence which he feels could begin to impact his mental health.

Phone calls were often offered by health services as an alternative to online access, but this led to concerns regarding phone signals, dependence on others and confidentiality. We spoke with Angela, who is in her 60s, who has been profoundly deaf since she was a child. Angela discussed her experience with medical professionals, making assumptions that she lacks hearing due to her age, when she has been deaf her entire life. Angela says that she feels her medical interactions should be private and she should be able to deal with them independently. She has one phone with the specific loop system she needs to be able to hear but says that her doctor's surgery insists on having a mobile as their main method of contacting her. This means that she must have her husband or somebody else with her to repeat what is being said and so she cannot just go into a room and have a private conversation. This lack of autonomy and privacy upset her greatly.

Several participants reported that it is often assumed that those who need it, will have the support that they need, such as a family member or a friend to help when they are struggling. From our discussions, this is not always the case. One participant, Lisa, who was divorced and lived alone, described not feeling that she could bother anyone. There were also four participants from deaf or blind communities. They discussed how they already felt that their needs were not being catered for pre- pandemic, that they struggled to have that independence already and now they felt forced to contend with this extra layer. Hannah said *'you must think about access requirements for people who can't hear. Health outcomes for deaf people are already much worse than those for hearing or speaking people'*. Paul said: *'with sight issues, we are still trying to be fiercely independent. I battle a lot to try and keep my independence because if I was to give up on things I do now, even though I can only just about do them, it will start affecting my mental health'*.

Feeling valued and included

Several of the participants discussed feeling that they were being left behind, or that nobody cared if they were missed out. Carol, who is 96, and lives alone said *'quite frankly, I don't think we exist anymore, they can't wait to get rid of us'* and discussed how she has friends in their 80s who have shared similar thoughts on the matter: *'they're of the opinion they can't wait, they don't think that this country or the people in it can wait to get rid of their age group'*.

In the Unlocking the digital front door report, National Voices recommended that: *'No matter how people choose to interact with services they should receive the same level of access, consistent advice and outcomes of care regardless of channel. One size does not fit all.'* (National Voices 2021:4).

Conclusion

The insight narratives we created sought to illustrate some of the lived experience perspectives behind the statistics in terms of digital access to healthcare. Our aim was to enable practitioners, service providers and commissioners to understand the nature of digital exclusion and the reasons for it. These illustrations suggest a more nuanced and complex picture than one that can be solved simply by increasing access to technology and support. With the current shift to digital access, there is often a presumed inevitability that this is the only way forward. This can lead to an approach based on persuading people to use technology without respecting their preferences or understanding the reasons for them. As practitioners, service providers and commissioners, we need to ensure that these lived experiences and perspectives inform decisions on how people, particularly those from already disadvantaged groups, have choice and flexibility to access healthcare in ways that work best for them.

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