Unlocking the Digital Front Door:

Literature Review

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National Voices

Contents

Introduction

Covid-19 has changed the way people access services and accelerated a move to virtual and remote models of care. This has opened up many opportunities for efficiencies, innovation, and easier access, but has also thrown a spotlight on health inequalities, the barriers for people to access health and social care, and the digital divide.

In this next phase of the pandemic, with a move to NHS *111 First* and continuing digital first access to primary care, health and social care services will need to adapt in order to be inclusive and responsive to people from all backgrounds and with a range of needs.

This needs to be based on sound and granular insight into how people actually experience the new care models and what would help them to maintain, or even enhance, the way they access care.

National Voices commissioned this literature review as part of a [wider AAC funded project](#) to understand why and how people are digitally excluded and practical and innovative ways to make organisations and services more inclusive.

1   Research questions

This review set out to answer two questions:

- What does the literature tell us about digital exclusion?
- What is the scale of digital exclusion?

2   Literature Review Search strategy

The review is based on four sources:

- the **Patient Experience Library**;
- a small sample of documents identified by **National Voices**;
- additional searches to follow up citations from these two plus some additional Google Scholar searches on specific themes to provide wider context;
- and a small number of **Care Opinion** stories.

The *Patient Experience Library* contains over 60,000 publications on patient experience and involvement. These include surveys, studies and policy documents from sources including government bodies, patient voice organisations, health charities and academic institutions. It contains both formal literature and grey literature (defined as publications that are ephemeral, poorly catalogued, or hard to find). It does not contain documents that are held behind journal paywalls, or other literature that would normally be for sale from booksellers. Most of the content is from 2012 onwards.

An initial search covering all documents up to the 23 November 2020 and including both UK and international documents was carried out, using the following search terms: apps, data, digital, digital divide, digital exclusion, digital inclusion, NHS 111, remote, telehealth, telecare, virtual. This initial

search delivered 3,009 results which were further refined to eliminate duplicates, retain only those up to three years old and to keep only those featuring the search terms as a prominent part of their content.

A further manual sort grouped the resulting 1,866 search items according to key themes:

- Issues around public trust
- Specific groups experiencing exclusion
- Digital healthcare in practice
- Principles for digital healthcare

These were reduced to items which were less than 3 years old (n = 1,165), and these were then refined for relevance. This review is based on the resulting 155 publications plus 13 more articles for which summaries were supplied by the *Patient Experience Library*; 14 publications supplied directly through *National Voices*; and 8 publications which supplemented or elaborated the themes identified or provided broader context for them.

Finally, the *Care Opinion* site was searched, using the search terms: remote consultation, video consultation, telephone consultation, online CBT. Of course, those who are digitally excluded are less likely to post accounts of their experiences on an online platform, so it is unsurprising that the resulting 116 stories were predominantly describing *positive* experiences and expressing appreciation. However, the 12 stories that were critical give some indications of how patients felt excluded not from but through the use of virtual and remote forms of health service delivery and these have been included in the report as illustrative examples.

3 Defining Virtual and Remote Health Exclusion

NHS Digital (2019) defines digital *inclusion* and identifies *barriers* to it. Inclusion encompasses:

- Digital skills – being able to use digital devices such as computers or smart phones and the internet
- Connectivity - access to the internet through broadband, wi-fi and mobile
- Accessibility - services need to be designed to meet all users' needs, including those dependent on assistive technology to access digital services

They expand on how a lack of these, together with other 'supply' and 'demand' side factors, constitute barriers to inclusion:

- Awareness - not everyone is aware of digital services and products available to them
- Access - not everyone has the ability to connect to the internet and go online
- Confidence - some people fear online crime, lack trust in virtual forms of information and communication or don't know where to start online
- Skills - not everyone has the ability to use the internet and online services
- Motivation - not everyone sees why using the internet could be relevant and helpful
- Design - not all digital services and products are accessible and easy to use
- Staff capability and capacity - not all health and care staff themselves have the skills and knowledge to recommend digital services and products to patients and service users

Both the Green paper on Prevention and the NHS Long-term Plan portray new digital approaches to healthcare delivery as helping to address entrenched health inequalities (See Section 2 for further details on these). The potential for technologically delivered healthcare to reproduce health inequalities by excluding some sections of society receives far less attention. This is important in the light of the most recent Marmot review (Marmot et al., 2020) which revealed how ongoing and enduring health inequalities are continuing to rise, and how positive health outcomes are actually falling in some of the most deprived areas.

The Health Foundation (2019) outlines some of the potential risks in relation to *public health and prevention,* where targeting can amplify rather than reduce health inequalities. For example, the current NHS Health Check programme is effectively universal for 40–74 year olds, but since people who take up health checks tend to be healthier than the general population, the programme brings more benefit to people who had better health in the first place. People living in more deprived areas or with fewer social connections are less likely to participate in preventive health services including some cancer screening programmes as well as routine health checks. The authors of the report recognise that moving services to digital channels could expand access to care, reduce any stigma associated with accessing them or help people fit them in around work and family life. But while data-driven technology could be used to monitor the impact of the health checks, employing linked data to identify and target those members of marginalised groups not currently reached by prevention intervention, the data systems used to do this often reflect structural inequalities at design-level. For example, people of European ancestry make up 79 percent of all participants of genetic studies so that historically the many risk-prediction innovations based on genetic datasets have excluded specific populations.

Similarly, even in a health system that provides universal access like the NHS, electronic health records will contain biases. For example, some groups may be less likely to seek treatment or may receive a different diagnosis if they do, so that their needs will not be captured in the data. Algorithms can perpetuate or reinforce existing biases in risk assessment processes since those who are least able to access appropriate healthcare are the most likely to be under-represented in data sources. Balancing the benefits of data and technology solutions against the risk that they will exclude some populations, therefore, is a major challenge: "It is important to apply data and tech solutions in ways that reduce health inequalities and benefit those most in need. This includes addressing explicitly the impact of new solutions on health inequalities, taking into account the barriers that some groups face…" the authors conclude (Health Foundation, 2019, p.13).

A British Heart Foundation report for the All-Party Parliamentary Group on Heart and Circulatory Diseases echoes these risks in relation to the use of AI; here, lack of representation of people from Black, Asian, and minority ethnic (BAME) communities in clinical trials may mean that AI could work less well for them and other under-represented groups. These risks were also recognised by the Academy of Royal Medical Colleges (2019), and the independent Topol Review (2019), undertaken on behalf of the Secretary of State for Health and Social Care. The British Heart Foundation report (ibid) recommends that NHS England and NHS Digital should expand their programme of work on digital inclusion and digital literacy specifically to explore the potential impact of wearables and AI on health inequalities and begin working closely with charities and think tanks across different sectors in order to design strategies to mitigate potential inequalities.

On a positive note, the Topol Review recounts that the NHS Digital's 'Widening Participation' programme has achieved scale and reach, with people learning to access health information online for the first time, feeling more informed about their health and confident about using online tools to manage their health (see Sections 6 and 8 for more on the Widening Participation programme). But it remains a cause for concern if virtual and remote care is uncritically seen as a solution. NHS 'Digital First Primary Care', for example, sees the development of digital general practice as central to reducing health inequalities experienced by 'under-doctored' patients in the most socio-economically deprived areas, by providing extra capacity. This is unlikely to be effective, however, if the paradox inherent in adopting a digital 'solution' to health inequalities for those (socially-excluded) groups who are among those most likely *also* to be *digitally* excluded, is not recognised and addressed.

Developments in data-driven, remote and virtual care have been accelerated, however, by the Covid crisis. The Nuffield Trust (Hutchings, 2020) reports that the Covid-19 pandemic has resulted in a more rapid adoption of digital technology in the NHS with primary care in particular seeing a huge increase in remote appointments, but also increased registrations for the NHS App, NHS login and e-prescription services. In March 2020, guidance was issued to primary care providers, stating that all patients should be triaged before an appointment, ideally through an online consultation, and that remote appointment options should be used, where clinically appropriate, to reduce the risk of infection from Covid-19. The same month, online consultations doubled from around 900,00 to over 1.8 million (Bibby and Leavey, 2020). A majority of general practices have now switched to a system of 'total triage,' according to Hutchings (ibid), with 99 percent of GP practices using remote consultation platforms to triage patients before offering them an appointment according to their particular needs. But not all patients have experienced this as a positive development. Some early indications of difficulties experienced in relation to e-consultations and referrals, for example, can be seen in *Care Opinion* reports:

"Completed an online request for an E consult, promised contact by 6.30pm the following day. No response. Link on original email if not contacted, so used link. Confirmation received, would be contacted shortly. No response. Tried to call the phone number provided twice over the next week but can't get through as when you press option 1 to speak to a receptionist, it's constantly engaged.   What more can I do? ("Requested an E Consult", *Care Opinion*)

"I recently phoned my GP practice during opening hours for advice as my child had a minor injury following a bike accident and wanted to know whether to go to A and E or whether a video consult with GP may do. Reception advised me to fill in the e consult form and look for the section 'Get help for my child'. I dutifully did look on there and found no reference to injury/accident. My child was in pain and I should probably have trusted my instincts and gone straight to A and E which I did in the end. I eventually found an e consult form to complete on my child's behalf which took an absurdly long amount of time to complete, and anxiety provoking. I submitted this and an hour later received an email advising that I should take my child to A&E. In ordinary times if I phoned my GP practice reception staff would probably have used an algorithm to advise me over the phone what action to take. I can't fault my medical practice as my experience of them over the years has been excellent...I just felt this e consult de-personalised the experience of care." ("E-consult difficult to navigate", *Care Opinion*)

"Tuesday afternoon I called my GP Surgery, I explained my 8 month old was continually dropping his head and crying, then tensing his arms and crying, I was advised the doctor would call me back Wednesday morning. Wednesday morning a doctor called me, I have never spoken to such a patronising person, the first words were 'why am I calling you? '. Instantly that upset me, as there didn't seem to be any care. I explained about my 8 month-old dropping his head and it was getting worse, I explained he was crying while doing so, and was just told that "babies do these things"? I said this isn't normal for my son. I was asked what I expect them to do, as they aren't seeing patients. I feel that this is an absolutely disgusting attitude, my son was showing major signs of infantile spasms and they were refusing to see him. I knew they were seeing patients as in the call I made the afternoon before the receptionist had informed me the doctor might want to see my son and they are staggering appointments due to COVID 19. I said that I have videos to show and the doctor said 'how do you think I'll see them? ' This was not a good experience." ("Doctor refused to see my son", *Care Opinion*)

"The helpful secretary at my new GP, who was great, suggested a phone consultation because it would be the fastest way to get a specialist referral and they said to mention that all the documents were in my file that the phone GP has access to. The GP … asked me to say what is wrong. I began to explain the situation and was cut off to be asked again 'what is wrong?'. I started to describe my first symptoms …The GP cut me off to say I have to have an in-person assessment with my GP to check that it's not ear wax build-up or an infection. Then they hung up. The entire call lasted 2 minutes and I didn't even catch their name; if they told me (?). I now understand this is a service called Practice Assist run by Care Uk… I am really disappointed and will not opt for GP consultation by phone again. It is a service that only works if the doctor is willing to listen for more than 2 minutes." ("GP Phone Consultation", *Care Opinion*)

"I'm trying to self-refer to the podiatrist assessment centre … Not only do they make the form only available as a PDF, which is difficult to edit, they have no email address to receive the completed form. We are in the throes of a digital healthcare revolution but not being able to use technology from the 70's to communicate with healthcare providers is a little worrying. I have poor handwriting and being able to type notes and complete forms digitally makes life easier for everyone. Luckily I know how to edit a PDF but making a Word version would make life easier." ("Accessibility issues with digital communications for self-referral", *Care Opinion*)

Healthwatch Derbyshire (2020) has also undertaken research into people's experience of virtual appointments during the Covid-19 pandemic. They report that while satisfactory for some of their respondents, virtual appointments did not work for many others and at times were inaccessible to specific categories of digitally excluded patients, including children and young people (aged 25 and under); those who were deaf or who had a hearing or sight impairment; those with learning disabilities; and those with mental health conditions. Participants who faced barriers during their attempt to access an appointment were less likely to have a positive perception of virtual appointments, even if the method of appointment was suitable for their needs.

In such a fast-moving environment, therefore, it is important to take stock of the impact of these new developments on all our citizens, especially when those in most need of healthcare are also among those most at risk of getting 'left behind'. As Hutchings (2020) observes, concern has been expressed that the increasing use of digital health tools might exacerbate rather than alleviate health inequalities if people are unable to use or access digital alternatives (Scobie, 2019). This could

be a result of limited digital literacy, confidence or skills as well as limited access to technology such as a smartphone or the internet. What is consistent, as Scobie reports, is evidence that people who are most vulnerable and have the greatest health needs are least able to access digital services. Given the rapid expansion of these during the Covid-19 pandemic, therefore, and the desire to capitalise on such 'gains' in the future, fears that a 'digital divide' will worsen if remote ways of accessing services become more mainstream cannot be ignored. Further, tackling issues around social and digital inclusion/exclusion and health inequalities needs to include a better understanding of what the implications of using 'digital-first' are for *different groups of patients*, including the ways that remote forms of service delivery such as video-consultations change the nature of an encounter (see, for example, the 'interactional challenges' of post-operative oncology video-consultations highlighted by Stommel et al, 2019).

4   Taking a critical approach to the promise of virtual and remote health

The King's Fund (Castle-Clarke, 2018) has identified four current trends in technological development with the potential to improve healthcare:

- Genomics and precision medicine which can target treatment interventions at specific sub-groups of patients, potentially making them more effective and opening up new therapeutic possibilities
- Remote care which can improve access to healthcare services, enabling patient needs to be addressed as early as possible and potentially making systems more efficient.
- Technology-supported self-management which can help to empower patients to better manage and understand their condition, supporting improved behavioural and clinical outcomes.
- Data that can provide new ways for the NHS to learn, improve and generate new research – alongside artificial intelligence (AI), which is providing new analytical capacity for diagnosing patients, effective triage and logistics.

As the Health Foundation (2019) points out, advances in genetic sequencing, machine learning and artificial intelligence (AI) could all usher in a new era of more personalised interventions underpinned by more precise risk prediction. Large-scale NHS investment in AI to make better use of data and technology is central to the government's Prevention Green paper 'Advancing our health: prevention in the 2020s'; and in relation to the potential of remote care to improve access to healthcare services, the ambition of 'The NHS Long Term Plan' was that all patients would have a right to online GP consultations and access to a 'digital-first' primary care offer by 2023/24. The Plan states:

"GP practices and hospital outpatients currently provide around 400 million face-to-face appointments each year. Over the next five years, every patient will have the right to online 'digital' GP consultations and redesigned hospital support will be able to avoid up to a third of outpatient appointments - saving patients 30 million trips to hospital and saving the NHS over £1 billion a year in new expenditure averted" (p.6).

The aim is that:

"Digitally-enabled primary and outpatient care will go mainstream across the NHS - Digital technology will provide convenient ways for patients to access advice and care…Then, building on progress already made on digitising appointments and prescriptions, a digital NHS 'front door' through the NHS App will provide advice, check symptoms and connect people with healthcare professionals – including through telephone and video consultations. Patients will be able to access virtual services alongside face-to-face services via a computer or smart phone" (pp.25-6).

There were examples of all of the above trends in the literature reviewed, including: the use of electronic health records (EHRs); the remote monitoring/integration of symptom data into EHRs, for example, of rheumatoid arthritis via a smartphone app (Austen et al., 2019); patient data sharing within and beyond the NHS for research purposes; promoting self-care via apps supporting exercise and weight control; the use of NHS mail for digital rostering and visit-logging by care home providers; early interventions with children and young people via games and apps such as 'ChatHealth' (Martin et al., 2020); data-driven approaches to cancer care (Reform, undated); and the NHS App itself, which runs on a smart phone or tablet and aims to provide a way for people to book GP appointments, order repeat medication, see summary records and find about what to do if they need urgent medical care or find health advice.

Evidence on the effectiveness of video consultations is scarce. (Car et al., 2020). What there is suggests high levels of patient satisfaction but it should be borne in mind that this is based on a small number of small studies based primarily on hospital consultations. Doctors' attitudes, meanwhile are mixed. While they recognise possible benefits of video versus telephone consultations by providing visual cues and easier rapport building, they also highlight concerns around burgeoning workload, reimbursement and privacy. One can surmise that, in line with evidence cited in this report on other health professionals, there may also be variations not only in the availability of suitable infrastructural facilities but in levels of skill and confidence. Few if any physicians will have had specific training in conducting video consultations, not only in terms of changes to the dynamics of interpersonal interactions and communications posed but also in relation to rapidly evolving data protection and telehealth regulations (ACI, 2015; Shaw et al., 2018; AMA, 2020). [Some guidelines to conducting video consultations appear in Section 8].

It is also the case that in the literature reviewed, the prevailing emphasis (occasionally with proselytising overtones) is on how technology can enhance the delivery of care and its outcomes. Even when a project's stated aims include an investigation of both facilitators *and* barriers, it is sometimes difficult to identify findings on the latter. For example, in a report of a large-scale international investigation of using technology to design and deliver better mental health services (Cotton, 2019), the 'findings' consisted primarily of descriptive case studies, with the only specific mentions of issues of inclusion/exclusion being a passing reference to possible 'stigma' and a 'lack of availability of easily accessible services'; and in relation to the evaluation of one of the projects, a claim that it had been "successful in attracting some young people from marginalised and at-risk groups, as well as young people traditionally disadvantaged in their access to mental healthcare" (p.29), with no further explanatory analysis.

In another report on 'the potential of data and technology' for those with MS, a claim that "We have evidence (based on a small survey) that *most people with MS* (added italics) have a smartphone and are comfortable using the internet to find information about MS or to connect with other patients"

(Castle-Clarke et al., 2018, p.11) is in fact based on two studies, one of which used the online 'Survey Monkey' software to gather the views of 197 respondents, while the other collected the views of 51 respondents, some of these via an online forum - thereby itself excluding MS patients who do not use the internet.

A notable exception was a study by healthwatch Bucks (2018) which sought to find out what people thought about the telecare service (defined as the equipment and services that help people keep safe in their home and stay independent) they received from Buckinghamshire County Council. The researchers explicitly saw it as an opportunity to hear from a group of Bucks residents that they did not often reach. Assistive technology is being used more and more but they received very little feedback from people using it in Buckinghamshire. Consequently, they designed a survey with advice from the Buckinghamshire County Council telecare team and Carers Bucks, before sending out a letter and paper copy of their survey to 480 people, enclosing a pre-paid reply envelope (but also offering people the option of completing the survey online).

Even with the best of intentions in relation to enhancing inclusion, however, technology may be portrayed *a priori* as the answer – as it was in some research on palliative care and rehabilitation, in which "minority and hard-to-reach populations" such as "those living in vulnerable and social circumstances and/or living in remote geographical locations" have historically been excluded, (Brighton et al., 2018), but in which there was no recognition of the overlap between these groups and those who are digitally excluded. There are always resource constraints on the methods studies choose. For example, an 'inclusive' deliberative public engagement exercise on the use of a Test and Trace App (Traverse/Ada Lovelace Institute/Bang the Table/Involve, 2020) comments "we did not have the resources to involve anyone who wasn't already online" and that 'time and budget' constraints meant they had to forfeit the telephone interviews they had planned to ensure inclusion of the views of those who were less confident online. Similarly, the small number (n = 5) of patients receiving palliative or rehabilitation care who participated in the Brighton et al. project were recruited from those who were already members of an online forum and they participated in this project via online focus groups.

Nevertheless, there were some indications from the participants of factors that might enhance inclusivity for some of those not yet participating, such as having a less institutionally-designed home-page; using less institutional language; and offering more encouragement of patient-prompted topics for discussion. These observations may support the view of a recent editorial in the Health Service Research and Policy Journal (Editorial, 2020, p.139) which argued that approaches to improving patient experience, even some of those aimed at public and patient participation, still "continue to be hindered by a deeply engrained perception of patients and families as passive sources of data rather than active partners in implementing change" (Cornwell at al., 2015); and they also draw attention to findings on differences in terminology used by professionals seeking feedback and patients giving it, reflecting the acknowledged exclusion of patients and the public in the design, administration and evaluation of patient feedback questionnaires (Baines et al., 2019); and the need to use the kind of accessible language identified by 'Understanding Patient Data' (2017) (https://understandingpatientdata.org.uk/sites/default/files/2017-04/Data%20vocabulary_Good%20Business%20report%20March%202017_0.pdf)

It is certainly the case that the enthusiasm for virtual and remote health arises from 'professional' rather than 'lay' positions and perspectives and that, in the literature reviewed, when those engaged

in digital healthcare referred to 'barriers', it tended to mean barriers to *implementation* rather than barriers to *access* for the digitally excluded (see for example, The King's Fund, 2018). The need to take a critical approach is emphasised even more when it is suggested that healthcare is now part of a "post-digital world" in which "digital is no longer a differentiator" (Accenture, 2019).

5   Trust in 'technologised' health systems

As the delivery of healthcare has become increasingly 'technologised' and data-driven, new and innovative uses of patient data sharing with outside groups are appearing, such as Google Deepmind's 'Stream' App, designed to alert to kidney injury; proposals to make medical advice being available through Amazon's Alexa; and the development by Telefonica of an algorithm to predict mental health crises (Parkin and Loft, 2020). However, there is low public awareness of how patient data is used beyond individual care *within* the NHS (eg. Genomics, National Cancer registry), which is lower still in relation to its use beyond that (Understanding Patient Data, 2018). For example, the Corsham Institute (2018) observes that "At present, there is a gulf between the public's acceptance and use of services supported by cloud computing in other parts of their lives, such as online banking or photo storage, and their awareness that the NHS is holding their medical data using similar cloud services, particularly those owned or managed by non-UK third-party providers".

In the wake of the WannaCry cyber attack on the NHS in 2017 (Parliament Street, 2018) which affected about a third of hospitals in the UK and resulted in thousands of cancelled operations (Healthwatch England, 2018), the suspension of the national Care.data programme due to concerns over the opt-out system in place and over patient confidentiality plus a finding by the Information Commissioner that the Royal Free Trust failed to comply with the Data Protection Act when it provided patient data to Google DeepMind, it has become apparent that trust in 'technologized health' and its 'systems' is a major issue for the public. Further, Parkin and Loft (2020) report that in any US-UK trade talks, one negotiating objective of the United States would be to "Establish state-of-the-art rules to ensure that the UK does not impose measures that restrict cross-border data flows". In response, the UK Minister for Trade has said that "We would seek to review any rules in place to safeguard data... and ensure that they are not overly protectionist. We set up the pipework, but whether or not the taps are turned on is a matter for the regulators". Patients may or may not be reassured by this, the authors remark.

There is also a risk in relation to AI that the public could experience it more as a barrier than an open door, blocking access to care, offering opaque advice and dehumanising healthcare (Loder and Nicholas, 2018). Such distrust may be amplified if discourses around the possibilities and potentialities afforded by digital health technologies in general do not acknowledge the complexities and ambivalences that are part of using self-monitoring and self-care technologies for monitoring health and illness states, both for patients and for healthcare providers. These include the surveillance and disciplinary dimensions of using these technologies, Lupton (2013) suggests, the emotions and resistances they provoke, their contribution to the burden of self-care and the invisible work on the part of healthcare workers that they require to operate, all of which have implications for how people conceptualise their bodies/selves, health, illness and healthcare.

It is also the case that concerns about in/equality are an integral part of public trust. The British Institute for IT (2020) sees the issue of ensuring that new technologies such as contact-tracing Apps consider the implications for diverse communities, especially those mistrustful of authority, as an *ethical* issue; and in relation to the use of administrative data for research, for example, other studies have shown that once security concerns have been met, researchers must demonstrate a 'public good' outcome (Administrative Data Research UK, 2020; Health Research Charities Ireland, 2019) - although there has been some suggestion that how concepts of 'public good, 'public interest' etc. are in themselves constructed in ways that potentially reproduce social inequalities (Sorbie, 2020). Notions of public good not only excluded financial profit but included protections against specific geographical areas or demographic groups being negatively profiled, labelled or discriminated against. There are "significant gaps in our understanding of people's views, most notably around the perspectives of minority and marginalised groups' while "Some groups may have good reason to feel distrustful of the health and social care system and be inherently concerned that data about them could be used to target or discriminate against them". (Understanding Patient Data/NHS England/Ada Lovelace Institute, 2020). Evidence in the Administrative Data Research study on age and socio-economic status differences in trust was less clear, but there was some indication that it depended on how empowered/powerless people felt to deal with the consequences of a breach of security, so the emerging principle was one of engaging the public in design and decision-making on an ongoing basis. Similar concerns about engendering public trust in relation to the use of depersonalised health and care data sharing led One London (2020) to recommend using the 'Five Safes', a framework developed by the ONS (Stokes, 2017), which assures the public that when their depersonalised data are shared for research and development, this is only:

- completed by people who have been trained and accredited
- for research projects that deliver clear public benefits
- in a secure setting where it is impossible to remove data
- where all outputs are checked and confirmed as non-disclosive
- when the data to be used have had your name, address and any other variables that would directly identify you removed beforehand.

Engaging the public in design and decision-making on data sharing does not appear to be routine practice, however. A study by Understanding Patient Data/OneLondon/Curved Thinking (2019) identified specific kinds of data as particularly sensitive in the public's view: those relating to sexual health, mental health and history of substance abuse. But they also observe that there is very little published evidence on the actual views of those identified by others as in need of protection. In relation to London, for example, notable absences from published survey data are those from minority ethnic groups; diversity in relation to languages spoken; and areas with high rates of internal movement and population turn-over. In some initiatives designed to support virtual services, considerations of inequalities of access are also rather cursory or generic. The guide to 'online engagement' issued by the National Co-ordinating Centre for Public Engagement (2020), for example, advises those creating and running virtual meetings and events to "Make sure you know what the needs of your participants are, and put in place appropriate ways to engage them".

On the other hand, the NHS remains a highly trusted source of health information. However, technologically-mediated *misinformation*, constituting an 'infodemic', risks leading some sections of the public to exclude themselves from reliable guidance, for example in relation to Covid. Such

misinformation is reported to have "caused particularly acute panic and confusion amongst British Asian communities …" (House of Commons Digital, Culture, Media and Sport Committee, 2020). An IPPR report (Hochlaf and Quilter-Pinner, 2020) concludes that while new technologies have created opportunities to reach wider audiences, "It is also clear that the NHS and health sector more broadly need to take a more proactive approach. As an extremely trusted source of health information, it is imperative the NHS stays ahead of the curve".

6   Digital inclusion and exclusion: who, how and why

Who does digital exclusion affect?

In 2019, NHS Digital reported that eleven million people nationally (20 percent of the UK population) lacked basic digital skills or do not use digital technology at all, with a large proportion of 'non-users' being women. And in 2020, the Lloyds Bank UK Consumer Digital Index (2020) reported that:

- An estimated 9 million people (16 percent) are unable to use the Internet or their devices without assistance
- c. 6.5 million (12 percent) people cannot open Apps
- Two-thirds (66 percent) of those online have not used the Internet or digital Apps and tools to manage their health, either because they are yet to discover what could support them, or because existing related activities are not working for them.
- Of those using the Internet to manage their health, analysis of verbatim answers suggests that they are managing their physical and mental health by doing things like watching YouTube videos (e.g. to learn new things or to relax); playing online games (to unwind and de-stress); using digital Apps (e.g. for their gym memberships or to meditate); researching medical information through Google; and that these kinds of engagement were predominantly experienced positively.

A study of one specific area (Healthwatch Leeds, 2020), focusing on the potential of digitisation for reducing health inequalities, reported that prior to the coronavirus crisis, 90,000 adults in Leeds were without essential digital skills; 50,000 were not online at all; and 40 percent of council housing tenants were not online; while in Shropshire, a Food Parcel Coordinator observed of those visited during the pandemic:

"There seemed to be a massive gap between those who could use technology and those that could not. The lack of technical skills came to the forefront. There is a need for assistance to use remote appointments and a need to help someone learn the skills. We often found that as volunteers visited, so these situations were identified and people assisted." (Healthwatch Shropshire, 2020)

NHS Digital (2019) identifies those more likely to be digitally excluded as:

- 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 NHS Widening Digital Participation programme (Stone et al, 2020) added to this: people who face severe and multiple disadvantages (homelessness, substance misuse, mental ill health), those who are subject to racism and discrimination and those whose status as a refugee or as seeking asylum acts as a barrier. Other studies have identified some younger as well as older people as at risk, as well as healthcare staff themselves. These excluded groups are explored further below.

6.1 Those experiencing poverty/ low-income

Lloyds Bank reported that in 2019 nearly half of offline people (47 percent) came from a low-income household and 16 percent of benefit claimants were digitally disengaged – two percentage points down from 2018. Using 'access to the internet at home' as a measure of digital inclusion/exclusion, the Cambridge Centre for Housing and Planning Research (2020) **showed that inclusion increases with income**, such that in 2018 only 51 percent of households earning between £6,000 and £10,000 had internet access compared to 99 per cent of those with an income of £40,000 or more. Connolly et al (2020) observe in their review of Mental Health Apps, that "… ownership of a smartphone is not a sufficient predictor of successful app use. For those with **limited data plans**, the decision to download an app may mean sacrificing other functionalities on their phone and can therefore be considerable barrier to use". The Covid crisis has only exacerbated the extent of digital exclusion for those on low-incomes, with 1.9 million households with no access to the internet and tens of millions more reliant on pay-as-you-go services to make phone calls or access healthcare, education and benefits online. The Good Things Foundation, a charity that tackles digital exclusion in the UK, cited cases of families among the 25.9 million 'pay-as-you-go' customers who make up over a quarter of all mobile phone subscriptions in the UK, as being without the means to buy data or else spending disproportionate amounts of the weekly household budget on top-up credit, sometimes going without food to do so. In Manchester, a community network reported that almost 75 percent of the 1,000 women they supported were completely reliant on pay-as-you-go data services (https://www.theguardian.com/world/2020/apr/28/digital-divide-isolates-and-endangers-millions-of-uk-poorest). Keohne and Petrie (2019) suggest that this could in part be addressed by prescribing devices and wearables, where there is a clear health need, to individuals who cannot afford these products and by promoting digital access among individuals with long-term conditions, for example, through social prescribing of digital skills where necessary.

6.2 Older people

As Gallistl at al. (2020) observe, gerontological research has had the question of why older adults use or do not use the Internet on its agenda for some time. Early studies highlighted the relevance of psychological factors, such as a higher prevalence of computer anxiety, frustration with user interfaces, negative attitudes toward technology and higher concerns about security issues on the Internet, mainly regarding personal information. Older adults have been shown to face specific health-related barriers when accessing digital technologies, which are more challenging for those with for example, poor eyesight, shaky hands or cognitive impairment. Socio-economic factors such as lower levels of education and income have also been identified as predictors of older adults' internet use. On the other hand, it has been suggested that it may not be age itself, but rather the social positions and resources of older adults that determine internet use in later life. Importantly,

there is also the question of technological development and design, as research has noted that products are often poorly designed for older adults and therefore uncomfortable or at times even unmanageable to use. Healthwatch Shropshire (2020) and *Care Opinion* illustrate some views on interacting virtually from older people's perspectives:

"I don't like the idea of telephone and online appointments as I feel it shuts out the elderly patients. I have a neighbour who is 92 and she is too afraid to phone the doctor and have an appointment over the telephone so if she gets ill then she has isolated herself from the doctor." (Healthwatch Shropshire, 2020)

"She said she is not happy about having a doctor's appointment over the phone, she wants to sit and see her doctor face to face, she cannot read someone's facial expression or body language over the phone". (Healthwatch Shropshire, 2020)

"My parents are both in their 90s; Dad has terminal lung cancer and Mum is partially sighted with mild dementia and a history of falls. They have had very little input from their GP during lockdown and it has all been done over the telephone – as they are both hearing impaired this has not been easy. I appreciate that telephone/video appointments are much more convenient for GPs but I don't feel they always meet the needs of frail, elderly patients." (Healthwatch Shropshire, 2020)

"I'm over 90 and I don't like it (video-consultation). I do not like Zoom, it doesn't feel suitable for older people. I don't like to speak over the phone because I'm hard of hearing. Face-to-face is better. They wanted me to take a picture of my nose. I can't do that myself, no phone or camera. I can't do digital and computers without the help of my family so it's not suitable for older people like me". (Healthwatch Shropshire, 2020)

"Many elderly people who are managing alone are unable to use email or websites. Many find it difficult even to get through on the telephone. True, some 90-year old's are computer literate but the majority I believe are not. Not only the elderly are having problems, I know off many younger people who are just giving up contacting their local surgeries. I hope the planned way forward is not just a huge cost cutting exercise" (Healthwatch Shropshire, 2020: Age UK Volunteer)

"Kincorth Medical practice in Aberdeen must be the worst I have ever come across. I know we are living in unprecedented times, however their poor excuse for not visiting elderly and infirm patients is no PPE. Surely they can purchase and not use this as an excuse for not visiting patients that are in need of help, especially the really elderly and vulnerable that do not have access to the internet for a zoom consultation. I am already considering contacting the General Medical Board regarding this practice and the experience I and my family have encountered recently when a relative passed away and the refusal to send someone to help when they were actually dying." ("Lack of care", *Care Opinion*)

6.3 Children and young people

Despite the ongoing discourse about the constantly connected and digitally savvy youth in the UK, a growing evidence base demonstrates that there are still significant inequalities in young people's ability to access and use the internet. There is a small but significant proportion of young people who do not have internet access at home, or sufficient digital skills to engage online in ways that are meaningful to them (Wilkin et al, 2017). Furthermore, while young people use smartphones in their everyday lives, they have not typically associated digital technology with their healthcare (Healthwatch Central West London, 2020). According to an Early Intervention Foundation report (2020), virtual and digital health interventions aimed at young people often face high levels of attrition, with participants dropping out or failing to complete the intervention. Addressing this remains a challenge according to the report's authors, although there was some suggestion that interventions that combined some kind of personalisation and/or contact with a health practitioner rather than being completely self-directed and non-interactive, were more likely to improve outcomes. Incorporating personal contact within a digital setting was also supported by a study of undergraduates as 'second generation digital natives' (Cowey and Potts, 2018) as well as by the Healthwatch Central West London study (2020) and a Healthwatch West Sussex report (2020a).

The young people in the last of these not only pointed out that not all young people have access to (smart) phones, WiFi or the desired privacy for a health consultation but also identified factors militating against being otherwise inclined towards digital interaction, namely, the amount of time spent engaged in online schooling during the Covid 'lockdown' and how 'exposed' some young people felt in video meetings. On the other hand, the use of an App featuring an animal character was shown to empower paediatric patients in hospital to influence and inform the care they received, in contrast to previous surveys conducted by the hospital, which had been inwardly focussed on staff perspectives or parent-driven. The use of the App in this context, therefore, created a more inclusive approach to a patient group who had previously been effectively excluded from their own care (O'Neill et al., 2018).

Comments from the Healthwatch West Sussex (2020b) report illustrate some young people's experiences of virtual consultations (findings supported by Healthwatch West Sussex, 2020c). Some of these experiences describe what might be called 'intra-consultation exclusion':

"Had a GP consultation on the phone but had to wait all day whilst at college. This meant I had to tell my teacher so I could leave the classroom. This was embarrassing, and it also meant everyone saw I had to leave. Knowing a time would have been useful so I could be prepared. Also a text or email introduction. It was all too unknown and quite nerve-wracking. Being in college with nowhere private added to that."

"We had to have a digital appointment for an infected insect bite, but the connection was really poor and kept cutting out. The appointment lasted for ages as it took a long time to upload photos and then wait for emails about medication etc. We didn't know if information had got through."

"I don't like video calls just because I tend to be awkward and worried about accidentally saying something wrong or having my camera on when I hadn't realised, etc. I just kind of get worried for more reason than I should be."

[See Healthwatch West Sussex (2020b) in Section 8 for guidelines on how to make digital communication more inclusive for young people].

6.4 Women

Although the number of internet non-users[1] has been declining, in 2018, 58 percent (3.1 million) of these were women, a proportion that has remained broadly consistent over time. There is also a disparity between men and women in digital skills. Of those having zero basic digital skills in 2018, 61percent were women. (ONS, 2019). Some women were particularly at risk from being digitally excluded during the Covid crisis, as Rose Ssali from the 'Mama Health and Poverty Partnership' reported: "Women in situations of domestic violence are particularly isolated. Most of them have no access to their phones or the internet". Consequently, members of the charity were trying to find funds to buy pay-as-you-go handsets with some credit on them and hiding them in the food packages being delivered, to enable the women to call someone if they needed help. (https://www.theguardian.com/world/2020/apr/28/digital-divide-isolates-and-endangers-millions-of-uk-poorest).

6.5 *Members of minority ethnic groups*

The ONS (2019) showed that across the ethnic groups for which breakdowns were available, the proportion of non-users came down between 2011 and 2018. In 2011, there were wide disparities in recent internet use among the different ethnic groups. However, in 2018 this gap had narrowed. This was particularly the case for adults of Bangladeshi origin. In 2011, 31.4 percent of them were internet non-users, higher than the figure for UK adults overall (20.3 percent). In 2018, the figure for Bangladeshi internet non-users had dropped to 8.0 percent, a figure that was lower than for the UK overall (10.0 percent). In March 2020, people taking part in the BAME women's focus group convened by Coventry Healthwatch (2020) believed that lack of adequate IT skills would be a big issue for them and there was also concern about lack of access to smart phones, laptops or PCs; Unique Minds, a Leeds-based charity that supports men from BAME communities, including refugees and asylum seekers reported that its users did have access to devices during lockdown (Healthwatch Leeds, 2020); and Healthwatch Manchester observe from their survey of older residents that maintaining face-to-face contact with health professionals was considered important by the majority of respondents and that this issue was of particular importance to the Chinese, Pakistani and Indian respondents.

6.6 People with mental health conditions

Three main themes have been identified that maintain digital exclusion for people with mental health conditions: a perceived lack of knowledge; being unable to access the necessary technology and services owing to personal circumstances; and the barriers presented by mental health difficulties. Specific facilitators for overcoming digital exclusion for this group that have been identified include fostering intrinsic motivation and a personalized learning format tailored to the individual's knowledge gaps and preferred learning style (Greer et al, 2019).

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[1] "Internet non-users" refers here to those who have never used the internet or last used it more than three months ago.

App developers may not take these factors into consideration. The study by Connolly et al., (2020) reports that "More than 10,000 MH apps are available for download, offering features such as symptom and behavior tracking, diagnostic screening, psychoeducation, and relaxation and mindfulness exercises". Analysis of depression app trials has reported a dropout rate of almost 50 percent, however, and a median daily engagement rate of 4 percent. These findings, say the authors, "highlight a striking mismatch between the degree of enthusiasm, effort, and capital being dedicated to MH app development as compared to the extent of our knowledge regarding apps' effectiveness and their potential for sustained use".

Group sessions are a core part of delivering mental health services in the UK, but when the Covid lockdown measures were introduced, many face-to-face group sessions were initially stopped (Mental Health Network Briefing, 2020). As some service providers moved to delivering these via Zoom and then Microsoft Teams, they reported being aware of potentially excluding those without access to the internet or the requisite software, including: low-income households, some of those with a disability and some older people, without finding any solutions to this. Further, research by Best et al. (2019) revealed that while there were some perceived advantages to delivering group-based support to adults with depression via video-conferencing (such as staying in the comfort of one's own home, decreased anxiety around being 'in public' and being in a smaller group), there were also reports from some patients of what the kind of 'intra-consultation' exclusion referred to earlier, that is, they experienced a technologically-mediated service as inhibiting their participation, initially in terms of the need to overcome a skills gap and subsequently in terms of being less able to read and interpret non-verbal communication clues and (related to a need to work harder at this), a greater sense of being surveyed oneself.

"Very hard to ring because of anxiety. Subsequently put it off for ages and have also ignored other issues to avoid the phone". (Healthwatch Shropshire, 2020)

"A family member has been suffering with her mental health for a number of months now and today gained enough courage to call for an appointment with a GP to start getting help she desperately needs. After the way [they] were spoken to and made to feel by the receptionist it is making seeking help hard for someone who is already struggling with their mental health. **When you are faced with barriers such as unhelpful receptionists who are untrained it can actually cause harm to patients, make them feel like there is no help available to them or even that they are not worthy of help, which in turn could lead to undesirable consequences**". (Healthwatch Shropshire, 2020)

"My 14 year old daughter was referred to CAMHS in Feb and is still waiting to see someone. Counselling by telephone does not work for her. She needs a proper assessment and subsequent treatment. I understand that, where possible people should work from home/remotely but this is obviously not working for all patients and there should be someone available in person when required. I am concerned that her recovery rate will be severely affected by the length of time this is taking. **I feel very frustrated/angry that as a key worker I am expected to deal with 200 plus people each shift but it's impossible to find one person willing to sit with a young girl and help her get through this very difficult/dangerous time**". ("There should be someone available in person", *Care Opinion*)

"My 10 year old Daughter was seeing a counsellor from CAMHS at the Hamilton base, who was absolutely fantastic and gained my daughters trust fairly quickly and we felt as though we were making good progress....... then obviously Covid struck and kids were dismissed and discharged in a video call which was very emotional for all concerned. I was sent some links from our counsellor in order to help try and deal with this at home .... When contacting one of the links I was told that they did not deal with individual cases of support and I would have to go back to GP etc, this was very frustrating... I contacted my local GP, who was fab and said she definately needed to be referred back to the Camhs team again. This process was fab and very officiant I am pleased to say and before I knew it my original contact was back on the phone to try and help us out...... with a video call. This however was a bit of a disaster, between links not working and being lost several times, to the fact that it has been 5 months since my daughter had seen the member of staff, who she adored, so she was obviously very nervous, worried and completely out of her comfort zone and therefore a total closed book. **We are of course going to try a few phone calls between them both to try and open up the trust again…**" ("letting our vulnerable kids down", *Care Opinion*)

"I was referred by my GP for post natal health anxiety, following the death of a friend who was a new mum. My anxiety was awful and I was drowning in it. The therapist I went to seemed annoyed that I had my baby with me. I explained I had no one in a 200 mile radius to help me. Apparently that doesn't fit their no children policy. I told her there is literally nothing I could do about it. She said even in online sessions you arent meant to have a child around. I didn't want an online course in CBT anyway. I needed someone to talk it through in person. She said she would see what she could do. I made an appointment the following week. Then, I got a text message randomly cancelling my appointment. A few days later i got a letter saying they would no longer see me but I might benefit from some online CBT and just gave me a log in. What a fail. **Common sense would suggest that if someone has no one else around, they might need actual human interaction.** Didn't bother logging in. NHS money could be better spent elsewhere." ("Having no support made me non-compliant", *Care Opinion*)

"I self referred due to my extremely low self esteem, it is affecting my relationship and I didn't know where to turn. I completed a telephone consultation but on the same day received a letter saying it had been cancelled as they had not heard anything from me (I didn't think anything of it as the consultation went ahead). I was referred for online work to help and was told I would get appointments soon. 2 weeks later I received a letter saying they were closing their involvement as I had not been in touch! I rang the number provided and no reply over and over again**, I called when I could as I work full time.** I have emailed the email address 5 times in total, never getting a response, and now it is months later. **I just don't understand how it works, why is there no one answering phones or replying to emails?** And why are these closure letters sent when people are waiting to get help? I am just massively disappointed, after my original call I felt like I might actually get help, I can't afford private counselling and I felt positive." ("Self referral to Steps2 Change", *Care Opinion*)

And a number of carers described the challenges their loved one faces when only being able to have an appointment over the phone together with their own frustrations and concerns:

 "Absolutely shocking that my daughter who suffers from anorexia and has lost over 18kgs in under 4 months has not been seen face to face or monitored properly. Just a phone call a week telling her to weigh herself and check her BMI on the NHS website. No care plan, no bloods forms sent even

though she is meant to have weekly blood tests. **Given a number to ring if daughter is desperate but informed it might not be answered as there might not be anyone there**". (Healthwatch Shropshire, 2020)

"My daughter had a telephone appointment with her Psychiatrist and it was an unmitigated disaster. The psychiatrist wouldn't speak to me although he has met me before. My daughter can't do talking on the phone, she has communication difficulties. There was no information sharing on the phone. I felt that she needs her medication altered but he refused to do this. **I feel that there is a training need in how to have an effective consultation on the phone – it is a different skill.**" (Healthwatch Shropshire, 2020)

6.7 People who are neuro-diverse

An autistic respondent to Healthwatch Shropshire (2020) reported their experience:

"As I am autistic I don't like using the phone, this matter caused me major problems in getting to see a doctor. It took a long time to have access to the medical practice NHS email address then they did not respond, just kept sending me to 'askmyGP' without giving any help to set up." (Healthwatch Shropshire, 2020)

6.8 People with disabilities

According to the ONS, across all age groups, disabled adults make up a large proportion of adult internet non-users. In 2017 for example, 56 percent of adult non-users were disabled, much higher than the proportion of disabled adults in the UK population as a whole, which in 2016-2017 was estimated to be 22 percent. For non-users between 16 and 24 years, 60 percent were disabled in 2017, a proportion that is the same as for those aged 75 years and older. Lloyds Bank (2019) showed that people with a disability were 35 percent less likely to have essential digital skills; only 11 percent of those with a disability used assistive technology (eg. a screen reader) when going online and a fifth said there was no suitable technology for their condition to help them go online. Progress appears to be slow. By 2020, the Lloyds Bank UK Consumer Digital Index (2020) data indicated that 42 percent of people with an impairment have Low or Very Low digital engagement. It also revealed that 45 percent of survey respondents who were online used face and fingerprint identification for safe digital access. People were more than twice as likely to be using this technology if they had High digital engagement; among this group, 56 percent use these biometric recognition tools for convenience and safety. The data indicated that there is a significant proportion of people who stand to gain a lot from the technology who aren't currently using, however. There was some indication that skill and confidence rather than access may be a key barrier.

Other evidence on how people with a disability see the use of technology in relation to health paints a mixed picture. For example, some parents of children with a disability and special educational needs described how referral journeys could be improved and supported by technology, although there were concerns about data security and management issues as well as about access (Healthwatch Coventry, 2020). The potential of technology to improve record sharing and updating was appreciated, however. Overall, they were positive about the use of technology to access health and social care services – especially if it could facilitate the two being better 'joined up'.

Some experiences of people with specific conditions and impairments are illustrated below.

6.8.1 Deaf/hearing impaired

"I need to make an appointment with Stoke Mandeville Hospital from time to time to have my hearing aids checked. The only way to make an appointment for this is by telephone. **How bizarre and unhelpful it is that the only way for a NON HEARING PERSON to make an appointment with the Audiology department is by using the telephone, for which a reasonable ability to hear is required**. The Buckinghamshire Healthcare NHS Trust website says that it is possible to contact the Audiology department line number 01296 315725 by using text, so that would avoid the impracticalities of having to use a telephone, but that text service does not work. A page on the Buckinghamshire Healthcare NHS Trust says "Our aim is to put your needs first." This does not happen where a NON HEARING PERSON is not able to make an appointment because there is no NON HEARING MEANS OF COMMUNICATION to make that appointment. ("Deaf people cannot make appointments"

(*Care Opinion*)

"I am concerned that as a deaf person it is difficult enough having to contact services you require as I can't hear on the phone unless there is a mobile number you can text to or email address at the very least. I feel that deaf people and others with any type of disability are being forgotten. People are not Deaf Aware. I'm one of the lucky ones but my confidence is slowly being worn down. I speak for my deaf peers, those that can't speak, those that sign, those that only lipread **- what about our rights, what about our mental health – this will get worse and the sad thing is no one really cares**" (Healthwatch Shropshire, 2020)

"I don't like to speak over the phone because I'm hard of hearing. I tried to get a GP appointment they said I would have to have a phone appointment but my son rang and told them that it would not be suitable for me and they agreed to give me a face-to-face. It would be better if my son didn't have to call about it" (Healthwatch Shropshire, 2020)

A deaf *professional* reported:

"I work in social care and I have to do video calls to clients - let me tell you what it is like for me. I have to put up with fuzzy pictures, tell the client to lift their head so I can lipread, tell them to stop walking around, etc. You are now looking to see whether this is a way forward for future appointments? Not only do we have to struggle with technology that is at best poor quality, but users are not Deaf Aware." (Healthwatch Shropshire, 2020 Social care worker)

6.8.2 Blind and partially sighted people

"We need a revolution in the way the NHS and local councils make information available to blind and partially sighted people". Despite the NHS Accessible Information Standard, this statement from an eleven year-old RNIB report (2009) is still applicable today. Following the launch of the RNIB's 'Losing Patients' campaign, one Trust began to address the issue. The Mid Yorkshire Hospitals NHS Trust took steps to systematically record patients' preferred reading formats. People in the Batley area who cannot read print were asked to notify the NHS if they need large print, audio or braille. Mid Yorkshire worked with blind and partially sighted people to consider improvements in its IT system so they can easily identify patients that need information sent to them in a format other than standard print.

As the report points out, progress towards an inclusive health service cannot be made without IT systems being capable of supporting the change and this is even more the case in the context of 'digital first'. In 2009, the RNIB was told by NHS managers and healthcare professionals that the computer system they used could not support them in delivering accessible information to their patients. "All IT systems used by providers of NHS services must be capable of logging a patient's communications needs. They should prompt staff users to consider health information needs whenever a patient's file is opened or a referral is being made. Likewise, IT systems that are used in the production of health information, from appointment letters to test results and general information leaflets, must be capable of producing materials that meet patient needs", the report concluded. This is still not the case (RNIB, 2020), although Stone et al. (2020) report that the Leeds Hearing and Sight Loss service is currently building up expertise in the kinds of facilities different platforms offer to people with sensory impairments. The RNIB report highlights the impact of this exclusion on the experiences of two patients, the first in relation to an ophthalmology appointment and the second in relation to an appointment to discuss cataract removal:

"I registered for my health board's e-comms service. However, the next time I visited the eye hospital, the administration staff in the ophthalmology department had never heard of e-comms and were unable to provide correspondence in an accessible format. **As ophthalmology is one of the functions most likely to have patients who require alternative format information, I found this lack of awareness troubling and excluding.**"

"The letter gave me seven days to acknowledge and confirm the appointment by phone," he said. "If not done so, I would be placed at the end of the waiting list, effectively adding another four months' delay before being able to see someone at the hospital. If I missed the deadline again, the entire case would be cancelled, and I would require a new referral from my optician. I suffer from a chronic pain condition and was unable to use my scanner to read the letter. **By the time someone visited me, and was able to read the letter to me, the appointment had lapsed**."

6.8.3 Learning disability

A learning disabled respondent to Healthwatch Shropshire reported what they would like to see in relation to digital and virtual healthcare:

"I am learning disabled, things that I would like to see – all doctors, consultants and nurses to have public NHS email accounts and have a NHS directory of email addresses (controlled by the NHS), have a learning disabled ambassador (single point of contact, primary, community and hospital care) that will help to get the disabled person the right care or the right response, have an open marker on all NHS files to say how a person wishes to be contacted, marker to say the person has extra medical needs when contacting the person (me)". (Healthwatch Shropshire, 2020)

6.9 People with Dementia

Around 850,000 people in the UK live with dementia. Many are supported by friends and family members. Carers often struggle to manage their own health and wellbeing. While digital participation can offer 24/7 access to information and advice, provide practical support, social connections, help with relaxation, entertainment and pursuing interests, digital exclusion remains a significant issue among carers and people with long-term conditions. Some carers and people living with dementia may lack the confidence and the resources to give digital a try and the time to dedicate to learning new skills. There is limited guidance on how to ensure that the benefits of the

internet extend to people living with dementia and their spouses or other family carers. Even in the 'Digital Leeds programme', where the local authority and partners are committed to an ambition of 100 percent digital inclusion, barriers persist for this group. A few people with dementia were already engaged with 'Alexa' for setting reminders (about medication, appointments, exercise) and for accessing NHS health information online, but most were unable or had no interest in doing so. Concern about financial safety was raised by some carers. The project concluded that further work is needed in relation to this group (Stone et al, 2020).

"My mum was called by her GP reception to say that there would be a video consultation the next day. She has dementia and no digital life, so this was impossible. There was no follow up." (Healthwatch, *National Voices* & Traverse, 2020)

"I have been helping to run Zoom meetings for people living with Dementia and their carers. **I have noticed that carers have to work particularly hard to help their loved one engage with a screen. We need to understand how to facilitate involvement. Some people are disadvantaged by the use of technology while others can benefit**" (Healthwatch Shropshire, 2020: Professional from the Alzheimer's Society)

6.10 People living in rural communities

Philip et al (2017) report that there is a clear urban-rural digital divide in Great Britain and that poor digital connectivity threatens the social and economic health of rural areas. As the Local Government Association (2020) observes, "As engagement in services is set to become more digital, it is important now more than ever for people to have faster and more reliable connectivity or Wi-Fi options, particularly for those most vulnerable and at risk of social isolation". Given this, it is unfortunate that the Chancellor announced in November 2020 that only a quarter of the committed spending on broadband allocated across the next four years would be made available. Andrew Glover, chair of the Internet Service Providers' Association, said: "The announcement scaling back the government's ambitions for supporting broadband rollout in the hardest to reach areas is a blow to rural communities…. we urge the Government to ensure that this policy pivot does not lead to longer term digital exclusion of those in harder to reach areas." Sarah Lee, head of policy at the Countryside Alliance, said: "The spending review has prompted questions over when, how and whether rural communities will get gigabit broadband. This is a significant concern for rural communities … who now more than ever need better digital connectivity" (Huffington Post, 27/11/2020).

6.11 People living Complex lives

6.11.1 Living with homelessness

As Stone et al. (2020) for the 'Widening Digital Participation' programme observe, life expectancy among homeless people is far lower than the national average. Premature deaths can occur because of treatable medical problems, making improving access to healthcare for homeless people a priority. Digital exclusion is high and complex among homeless communities. Their exclusion from traditional health services may be due to health providers failing to meet their needs or to self-exclusion. Some have good digital skills but lack a device, cannot afford data or don't access public WiFi due to feeling or being made to feel unwelcome. Some have low digital skills and low literacy while others don't trust technology.

6.11.2 Living with alcohol or substance misuse

The multiple layered health issues of this group frequently overlap with those experiencing homelessness and mental health conditions. Stone et al. (2020) observe that this means they are often concerned about immediate needs rather than wider health and wellbeing. The authors identify overcoming a potential lack of trust and responding to what is important to the individual at any one time as keys to supporting the introduction of digital technologies. A member of staff at one of the pathfinder projects set up by the Widening Digital Participation project commented:

"I think it's easy to forget with our client group how resourceful they are even though they're transient and might be homeless or heavily into substance misuse … if they need information they are pretty clued up on where to access it so maybe not a surprise that they so quickly learned … If they're not resourceful they don't survive."

6.11.3 Members of Gypsy/Traveller communities[2]

Gypsy/Travellers communities have long been recognised as socially excluded. In relation to remote and virtual health, Scadding and Sweeney's (2019) exploration of digital access amongst Gypsy/Traveller communities across the UK revealed high levels of digital inequality:

- One in five Gypsy and Traveller participants had never used the internet, compared to one in ten members of the general population.
- Over half of Gypsy and Traveller participants said that they did not feel confident using digital technology by themselves.
- Only two in five Gypsies and Travellers surveyed said that they use the internet daily, compared to four out of five of the general population.
- Only 38 percent of Gypsies and Travellers (33 percent if housed) had a household internet connection, compared to 86 percent of the general population.

In addition to issues around low literacy and lack of skills and confidence, the barriers the authors identified were:

- Data running out - Of those surveyed, roughly one fifth of participants said that running out of data and not being able to afford any more was one of their biggest barriers to accessing the internet.
- Cost - A number of people who did not have a household internet connection said that cost was a prohibitive factor in this.
- Signal - A number of people who responded said that poor signal was a barrier to them accessing the internet. According to figures released as part of the Race Disparity Audit in August 2018, Gypsies and Travellers are the ethnic groups most likely to be living in rural locations with 24.7 percent of Gypsies and Travellers living rurally, compared to 18.5 percent of the general population. This suggests that Gypsies and Travellers may be disproportionately affected by challenges in ensuring high speed internet connections in rural areas.

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[2] Tammi (2020) notes that Gypsy/Traveller is an official term negotiated with members of the community in Scotland and used by governments and other policy makers – which aims to recognise and encompass the 'diversity of Scotland's nomadic tribes'. However, it is important to note, she says, that the term is a contested one both within and outside the UK and not accepted by all families, some of whom prefer to self-define as Travellers.

6.11.4 Asylum seekers and victims of trafficking

Studies of digital Maternity Services, for example the Maternity DMA Report (2018) and the London-based 'Happy Baby Community' (HBC, 2020) serving women asylum seekers and victims of trafficking act as exemplars of the challenges of keeping *all* members of this population group connected to vital healthcare services. For example, many don't have access to phone credit (or in some cases, phones). It is also probable that for people in this category, English is not their first language. Issues in relation to language are referred to further below.

6.11.5 People with limited English

It is also probable that for people in this category as well as some others, English is not their first language. Participants in a Coventry healthwatch study (2020) who did not speak English as a first language felt a lack of knowledge, understanding and language barriers would prevent them from using electronic methods to access services, citing as an example a lack of response to a request from their GP practice for a translator.

It is obvious that if/when people belong to more than one of these groups, the complexities of their lives will militate against digital health inclusion. Stone et al. (2020) observe that destitution, social isolation, anxiety, poor health, post-traumatic stress and language barriers are experienced by many of those struggling with the kind of complex lives described above. A recurring issue for those in these situations within the Widening Digital Participation programme was opening a patient account to access GP online services. This usually requires an address, a photographic ID and in-person verification of ID. Each of these is a barrier for people leading complex lives, with limited English language and/or lacking trust in services. Some organisations used their centre address as a proxy address and provided a vouching letter. But requirements to appear in person at the GP surgery made people much less likely to register. Inclusive service design can (and should) reduce this barrier; but as the project staff note, many of the issues (especially lack of trust) have deeper roots in people's experiences of services and in wider systems. For some of the most disadvantaged individuals, experiences like homelessness, seeking asylum, not being able to speak adequate English, and lack of trust in service providers or in digital technology itself can make even well-designed digital health services inaccessible. For these reasons, Ray et al. (2020) suggest that face to face healthcare provision and alternatives to online registration should be prioritised for people who are digitally excluded.

In addition to these 'organisational' barriers, several publications reviewed for this report (e.g. Institute of Public Care/Oxford Brookes University, 2020; Seuren et al., 2020; Woolham et al., 2018) identified a skills deficit among the healthcare provider workforce itself, and drew attention to the need for more training to address this if patients are not to be 'institutionally' excluded.

6.12 Specific health conditions

6.12.1 People living with cancer

As the Peninsula Cancer Care Alliance (2020) reports, there is pre-pandemic evidence that patients with cancer living in more remote, rural locations do not have equal access to virtual solutions (De Guzman et al., 2020).

There is also emerging evidence of the impact of the digital divide on cancer patients *during* the pandemic. For example, oncologists observed differential access to telehealth, timely diagnosis, and treatment for BAME populations (European Commission, 2020). In addition, a US oncologist reported that during the first four weeks of introducing video consultations, about 30 percent of patients were not able to participate due to lack of access to a smartphone or broadband telephone (Rajasekaran, 2020).

Given the differential access to telehealth observed in relation to cancer, despite the well-developed 'pathways' in operation in conventional cancer care, it seems likely that others with serious health conditions and in urgent need of treatment may be similarly excluded.

6.12.2 People living with Diabetes

The Covid-19 pandemic has particular implications for people living with diabetes in so far as factors associated with lockdown such as boredom, increased anxiety, disruption to sleep, more limited access to certain foods and to certain forms of exercise, can all contribute to increased energy intake and thereby exacerbate effective self-management. In this context, a UK-wide online survey was developed and distributed between April and August 2020 to people living with diabetes and their parents, carers, and partners by NIHR Bristol Biomedical Research Centre (BBRC) in collaboration with the Diabetes UK South West team (Sauchelli, et al, 2020).

It revealed that 37 percent of respondents with diabetes viewed the guidance and support received by healthcare teams during the pandemic to be of poor quality. In what was reported as a feeling of being left in limbo, patients were divided between those who focussed on their control, those who reported having given up on self-management and those who were managing temporarily but with elevated feelings of isolation.

Research has demonstrated that face to face peer support can improve clinical, behavioural and psychosocial outcomes in relation to diabetes management and some of these groups have shifted to technologically-mediated forms (Zoom, Skype, WhatsApp) during the pandemic. Though respondents to the survey expressed a need for more contact from their healthcare team, telephone and video consultations were thought to be acceptable replacements by some, if with some improvements, as this respondent commented:

"More expansion of online data availability (only some tests results uploaded), better synchronisation between GP and clinic data services, rapid adoption of telemedicine (video consult) services instead of clinic visits." – 62, type 1 diabetes.

The report authors recognise the methodological limitations of the survey constituted by the fact that it was distributed online, via professional networks, patient portals of research groups, and relevant organisations (e.g. Diabetes UK), thereby limiting participation by those who are less engaged both with their healthcare teams and existing support networks or are unable to access the required technology or are less familiar with it. Ethnic minorities and men were underrepresented despite efforts to raise awareness of the survey across these groups. As the authors observe, this is important given the higher prevalence of diabetes in ethnic minority communities. The number of respondents who were parents, carers or partners of someone living with diabetes was also very

small, so an additional survey has now been launched specifically to capture their views and experiences.

In light of the finding that virtual support was seen by some to be an acceptable replacement for face to face contact with health professionals, the BBRC facilitated the participation of 16 adults between the ages of 16 and 65 with diabetes in three focus groups in order to further explore perspectives on the desirability and efficacy of digitally-delivered peer support. In conjunction with Diabetes UK, this was followed up by designing a user-led project aimed at developing and evaluating written and video guidelines plus training modules for those wishing to run virtual peer support groups and those wishing to take part in them, prior to a national roll-out. The potential of such virtual peer support group is seen to reach beyond the pandemic, but only as a *supplement to* rather than *replacement for* the face to face support service that some will still prefer. Virtual support was seen to have potential for enhancing access for those experiencing barriers constituted by: distance, transportation, mobility, caring responsibilities, schedule and social anxiety. At the same time, it was recognised that there will still be financial barriers for some, for example, those without computers or internet connection, some older adults and those whose first language is not English.

Guidelines arising from the focus groups for those who are interested in/able to access virtual support included the following:

- Online meetings should not exceed eight members in order to maximise effective participation
- Each group should have two co-facilitators
- As facilitation requires a considerable level of confidence, including in the use of technology, volunteers for this role need training and ongoing mentoring
- Co-ordination between researchers, relevant charities and healthcare teams can ensure programmes that are accessible, user-oriented and appropriately monitored.

In late 2020, National Voices brought together a group of individuals and organisations involved in offering [peer support online](#) to discuss the ways in which online tools have been used to deliver peer support, both before and during the pandemic – this included what we know about who peer support online works for, and who might miss out. This work reflects the growing need for more people to be supported to manage their conditions without formal health services and the existing recognition of the strength of peer support in enabling people to do this, which creates a fresh opportunity to make the case for peer support and to improve access to it.

6.13 Other Issues

The Widening Digital Participation report (2020) also draws attention to the fact that factors such as gender, homelessness, language difficulties, age, socio-economic status, ethnicity, disability and specific conditions may intersect, compounding digital exclusion. For example, in relation to pregnancy, a pathfinder project in Dorset aimed to support pregnant women from socially excluded groups for whom registering their pregnancy online was a barrier; a pregnant and homeless woman was supported to register in a local library by a worker at the homeless shelter; and a couple who had no internet access and low English language skills were enabled through a telephone helpline to register their pregnancy and were then referred to a local 'Digital Champion'. In other cases, overlaps between age and socio-economic status acted as barriers. Dimitriadis (2020) points out that among older people who are in general at risk of digital exclusion (with only 47 percent of adults

aged 75 years and over having recently used the internet), only a fifth of over-75s in the lowest socio-economic group are using the internet. A survey conducted collaboratively between Healthwatch Tower Hamlets, Waltham Forest and Newham to investigate digital engagement in the Covid-19 pandemic (2020) also illustrates these overlaps. They found that the 16 percent of their respondents who were digitally excluded were more likely to be: of Black or Asian ethnicity; over 65; have a disability; be in poor health and worried about it; and less likely to be working and financially secure. Comments from some of those in their study illustrate some of the difficulties their participants experienced in accessing care remotely:

"Covid-19 information should be available on paper. Several elderly neighbours do not access the internet. We help each other out in the community. It would be good to have a leaflet with phone numbers for services. I think there has been lots of gaps. Our internet service has been very spotty".

"We contacted the internet provider and were scheduled to have a technician come and have a look, but they did not show up, and we have not been able to get in touch with the service provider since (on hold for 1-2 hours only to have the call dropped on the other end)."

"New online access to services is causing some problems for Age UK clients. Not only the difficulty in using new technology but the cost on data. Phone or food is becoming a choice that needs to be made."

"I have a work smartphone but I can't use too much data. I don't have any internet connection. I have a smartphone and a mobile data package which gives me data but I do not know how to use the internet so it is not useful for me. I also do not understand how the data stuff works on my phone. I only know that I have data on my phone because this is what I was told when purchasing the phone contract."

The now widely accepted 'social model of disability', which draws attention to the ways that that people are disabled by barriers in society rather than by individual impairments or differences, may be the most appropriate lens through which to view the digital exclusion of all the different 'groups' identified here.

The VCSE Health and Wellbeing Alliance, a partnership between voluntary sectors and the health and care system to provide a voice and improve the health and wellbeing for all communities, is working to improve access and quality of care for populations experiencing health inequalities in relation to digital care models. Key actions recommended by them to address the barriers faced by groups disadvantaged by digital exclusion appear in Section 8.

7   Digital healthcare in practice - some examples

7.1 Digital Primary Care – evaluation

The rapid roll-out of the NHS App has not yet allowed comprehensive evaluation of its effectiveness in terms of inclusion and exclusion. However, evaluation of the 'Babylon GP at hand' (BGPaH) might be seen as offering some limited indicative insights (NHS Hammersmith and Fulham Clinical Commissioning Group, 2019).

The BGPaH is a primary care practice that incorporated a 'digital-first' service model into an existing practice in 2017 and then evaluated it. The practice operates in North West London, commissioned via a General Medical Services (GMS) contract through NHS Hammersmith and Fulham CCG. It introduced a 'digital-first' model of primary care, primarily through use of a mobile app and video consultations provided by their subcontractor, Babylon. Ipsos MORI, working in partnership with York Health Economics Consortium (YHEC), and with advisory input from Prof. Chris Salisbury (University of Bristol), were commissioned by NHS Hammersmith and Fulham (H&F) CCG and NHS England (NHSE) in May 2018 to undertake an independent evaluation of the Babylon GP at hand (BGPaH) practice.

The host CCG for BGPaH, NHS Hammersmith and Fulham CCG, is made up of 29 GP practices and served a patient population of 231,004 people as of 1st January 2018. The borough is small but densely populated, with inequalities existing within small geographic areas. The Joint Strategic Needs Assessment (JSNA) provides a comprehensive local picture of the population health and wellbeing needs, summarising the residents as follows:

- A large proportion of young working age residents and a low proportion of residents aged 65 and over.
- High levels of migration in and out.
- The fifth lowest number of children of any London borough.
- High ethnic and cultural diversity.

The BGPaH partnership (formerly known as Dr. Jefferies and Partners) subcontracted the provision of the majority of essential in-person and remote services to Babylon. The 'offer' is based on an enhanced model following a digital-first service through a Babylon mobile and web application. The App includes a triage system based on a symptom-checker. This provides a recommended course of action (e.g. book an appointment or go to A&E), but does not provide a suggested diagnosis to the patient. Patients are not required to use the symptom checker and are still able to go directly to booking a consultation if they wish. Video (or telephone) consultations are available 24/7, 365 days a year, usually within two hours of request. All consultations are recorded and are immediately available to patients and their GP via the App. Patients are also asked to provide an immediate 'star rating' on their appointment along with a comment, which are monitored in real-time in order to act on any concerns. Patients requiring face-to-face appointments can do so at five locations across London. They are generally required to book a digital consultation first and are then referred for a face-to-face consultation if necessary. For selected services, e.g. cervical smear screening, flu jabs or vaccinations, patients can book a face-to-face appointment directly by calling the support team. If a patient develops an urgent illness which requires a face-to-face appointment but is not be able to visit one of the GP clinic locations, BGPaH advises them to call 111 so they can be directed to the most appropriate local service. New patients registering at the practice are automatically de-registered from their previous practice.

Patients registered at BGPaH are younger and potentially more affluent than patients at the average practice in London and nationally. The vast majority are aged under 45 (94 percent), and two thirds live in areas with high proportions of relatively affluent categories. Reflecting the fact that they are more likely to be young, working full-time, and living in London, they are less likely to have caring responsibilities for other people. Typically, they are healthier than those at other practices in the

CCG, even after adjusting for age. The largest disease registers for BGPaH patients are depression, asthma and obesity and historically they are higher users of NHS 111 and A&E than might be expected, given their age. They also want to see or speak to a GP quickly, and are proactive about seeking information and advice.

Overall, users were satisfied with the service; although there were some areas of dissatisfaction, it appeared that patients 'weighed up' advantages and disadvantages in order to make an informed and considered choice about using it. However, the BGPaH experiences higher de-registration rates than the London average, with patients most commonly de-registering after two weeks, women being more likely to de-register than men (comprising 60 percent of all de-registrants). Around half (47 percent) of those de-registering returned to their original practice. There were three key reasons put forward by these patients for de-registering: dissatisfaction with the quality of care provided; a desire to be able to book a face-to-face appointment without having to have a digital appointment first; and a change in health needs. However, the evaluation was not been able to answer the question as to why so many patients leave so quickly after joining the practice.

Given the profile of those accessing the service, it can be inferred that the service is not being used by large numbers of older people, or large numbers of people with more complex health needs. In addition, given the nature of the service, people with no access to a smartphone or who are not comfortable using a smartphone are less likely to use it. This clearly limits the number and type of patients that are likely to use the service, with potential implications for health inequalities. There are indicative findings here that should be of note to those interested in evaluating the new NHS App's ability to enhance or exacerbate digital inclusion/exclusion.

7.2 Email consultations in primary care

In the United Kingdom, prior to COVID-19, just six percent of general practices reported offering email consultations to all patients; however, 21 percent of individual GPs reported using email to have a consultation with a patient, reflecting the unstructured nature of this phenomenon in the UK general practice. Based on 100 email consultations from two practices, totalling 262 individual emails in all and involving 85 different patients, Atherton et al. (2020) conducted a content analysis. Most of these email users were older than 40 years and over half were male. The consultations were mostly short and completed in a few days. Emails were mostly sent and received during the day, were mostly clinical in content rather than administrative and covered a wide range of clinical presentations.

Although the practices had different deprivation scores (using the Index of Multiple Deprivation), they were both in the least deprived deciles. Both participating GPs were male, relatively recently qualified, had been using email consultation for five years with selected patients and offered patients only informal guidance on how to use it. A total of 13 email consultations included an attachment: nine of photos, two documents containing monitoring data (blood sugar levels and blood pressure), one was a fact sheet and one was a form. In eleven consultations, the contact was from carers on behalf of patients, four of which were about children and seven about adults.

In thirteen emails, the GPs directly requested the patients to come in for a face-to-face consultation rather than continue the email consultation. It was patients who were largely responsible for initiating an email consultation, with multiple email consultations being initiated from the same patients within the data set. Emails functioned as a way for the patients to request an action, for example, a change in a prescription or to ask directly for a test result, circumventing the administrative processes already in place to allow patients to request these particular actions from a GP. Where GPs initiated emails, it was for obtaining and/or providing information following up from a face-to-face consultation, for example, sending a link to a website on contraception choices or updates. So it was not only a way to contact patients but was also used to devolve responsibility back to the patients. In one email, a GP referred to having tried to call the patient and using email as the secondary option, as it was not possible to reach the patient via telephone, thus leaving the responsibility for the contact with the patient.

Some consultations reverted to face-to-face consultations. An implicit working threshold was reached in the communication that led to the GP requesting this. The authors identified potential safety issues linked to the medium, for example, a delayed response that could be an issue for urgent enquiries. As email consultations are remote and asynchronous, there is potential for emails to be missed or not read, without this delay in communication being immediately apparent to the patient or GP. The authors saw email consultations not as a replacement for face-to-face ones but as having the potential to provide an additional form of access for patients. There are caveats, of course, given not only the small scale of the study but also the demographic status of participants. Nevertheless, the findings raise the question of whether this form of virtual consultation could have the potential to be more inclusive of men, whose higher morbidity levels have traditionally been associated with gendered reluctance to seek healthcare at the earliest opportunity.

Having said that, male respondents to a survey of patients' views and experiences of remote consultations by Healthwatch Enfield (2019) reported using online services offered by the GP slightly less than their female counterparts (27 percent to 33 percent), factors such as not being computer literate, not having access to equipment and not understanding how to use the system being identified as the main barriers to uptake of GP online services. Further, many of those from all groups experienced technological difficulties registering and logging in. A pandemic that ushers in remote forms of healthcare at pace doubtless also leaves little time for the kind of routine monitoring and evaluation described in the last example. Early findings on examples of practices like email consultations, however, suggest that evaluation is vital for assessing types and levels of inclusion and exclusion.

7.3 Social Care

The Local Government Association (2020) reports that over the last decade councils have lost £15 billion of core government funding. Additional cost pressures and income losses as a result of the pandemic leave the sector with a funding gap of £7.4 billion. In adult social care, only 4 per cent of Directors are fully confident their budget is sufficient to meet statutory duties. It is not surprising then that this reduces the ability for councils to invest in technology and digital services, to innovate at scale or move beyond one-off funded projects. The report authors see working with communities to enable and support digital inclusion as not so much about 'digital' as about 'people' and their report has collated a number of practical examples from around the country to illustrate this. Leeds

is one of these. Local health and care system leaders in Leeds city council have embraced a city-wide approach to digital innovation. Shared governance arrangements, joint digital posts and pooled budgets focussed on Health and Wellbeing Board objectives guide the city's approach to digital transformation.

It is supported by the wider '100 per cent Digital Leeds' programme which takes a community approach, in collaboration with local organisations, to actively tackling digital exclusion. Through the programme, residents of the city can develop their digital skills and confidence by borrowing technology through the tablet lending scheme and access support through digital champions. The scheme has over 1,000 trained volunteers at hand to provide digital support to anyone who needs it.

In another initiative as part of the national offer of support to the social care sector, NHSX partnered with Facebook to provide over 2,000 portal devices (tablets) to help those in social care settings connect with family and friends through video calls when visiting was restricted during lockdown. A number of areas have been involved in piloting the devices in care homes, including North Yorkshire County Council, Staffordshire County Council and Stoke on Trent Council. In North Yorkshire, use of the portals is part of a suite of support offered to council-run care homes across the county. In collaboration with services managers, care workers and with feedback from families, a package of support (including three different video calling solutions) were provided to each of the ten care homes. Feedback has been positive, for example, in one care home the use of video calling enabled residents and families to celebrate VE day. Most people preferred devices which are portable as they are easier for staff to move around the care home and hence better support private calls.

7.4 Whole system change

The largest category of publications from the *Patient Experience Library* was that providing examples of digital healthcare in practice. Apart from the single, local interventions, a typical example of whole system change is the model offered by Tollgate Medical Centre (Tollgate Medical Centre/Digital First/NHS, 2020) for converting wholesale to a remote system of clinical triage. Thorough and helpful as it might be for practices wishing to make similar changes, no real examination of how certain groups might be excluded seems to have been undertaken, beyond mentions of "vulnerable" patients who "may be disadvantaged by the Online Consultation process and miss out on appointment slots" or who "may find the new system intimidating and forgo contacting the surgery". No definition of vulnerability in this context is offered, although "regular and clear communications between the clinical and reception team" is seen to be needed to "support the identification and safeguarding of vulnerable patients"; the front-desk team are (to be) "equipped with a script, reminding them of the protocol for vulnerable patients", "frequent, regular and clear communications between the clinical and reception team (will) support the identification and safeguarding of vulnerable patients" and all practice staff will attend "relevant patient safeguarding training" to help them identify vulnerable and high-risk patients. It should be said, however, that the implicit definition of (clinically) 'vulnerable' in operation here is not necessarily synonymous with those patients identified in this review as vulnerable to digital exclusion.

7.5 Patient experiences during the coronavirus pandemic

There is no doubt that remote and virtual healthcare is qualitatively different from face to face encounters (in ways yet to be fully researched) and that rapid developments in these modes of healthcare delivery have left some behind. Covid-19 has accelerated these changes and some of

those interviewed for Traverse (2020) about the impact of coronavirus on their access to healthcare commented on these qualitative differences:

"On the phone [with the nurse] it was very different. Normally, I tell her things you don't tell anyone else… But the phone call was a bit more matter of fact…I'm sure if I had brought it up, she would've spent the time, but I'm holding back. I wasn't prepared."

"Communication is very functional and like we have bigger fish to fry."

All had had some prior experience of remote care, either by telephone, video or through an App, ranging from those who were familiar with using technology in other aspects of their life and happy to adapt to something they saw as efficient, to those who struggled with the change:

"I phoned my GP, I am a technophobe, I phoned them up. They told me to download the app. I said sorry, what's an app?? I need a prescription. She said she would help me as a one-off but I did get the medication."

The use of Apps was in fact highly variable, sometimes within a single case. For example, one pregnant participant had been recommended three separate Apps to access different information, but still managed to miss an appointment until the day after it, when a letter arrived in the post to say it had been cancelled. Where staff were uncertain about how the technology works this added to the confusion. In many cases telephone calls were strongly preferred, because they allow for questions, which was both practically and emotionally valued.

There were also mixed views about how useful remote appointments are. For some, it added little-to-no benefit over a telephone call, and in other cases neither approach was able to make the assessment their condition needed. In contrast, a post-stroke physio session via video proved invaluable and exploration of why this was the case for this patient revealed that despite being qualitatively different to a face to face session, the healthcare professional was still able to make it 'human'.

One of the most frequently mentioned remote communication tools was the answerphone. Answerphone messages had a strong influence both on people's behaviour and their experience of care, varying from messages telling people to go online unless their condition was urgent, which put them off asking for help, to confusion as answerphone messages were out of date. In contrast, a carer reported the experience of a telephone appointment for someone with a learning disability. Since the appointment wasn't scheduled for a specific time the carer wasn't able to be there, and it wasn't clear afterwards that a shared understanding had been reached between doctor and patient about changes to medication, requiring the carer to google the tablets to find out what they were for:

"Afterwards he knew that his tablets are being changed but not why. When he's on his own he downplays things, either because he doesn't understand or doesn't want to make a fuss".

7.6 People living with cancer

A King's Fund report (Collins, 2020) of a technological innovation to offer a new kind of support for cancer patients who feel isolated from friends and family between appointments and after treatment, (and who sometimes withdraw in the face of serious illness), used an App to enable them to build support networks. Patients and families downloaded the App, invited friends to join their network, and used the App to ask friends, peers with experience of cancer and trained volunteers

for support (using a map to find peers and volunteers in their local area). Rather than contacting people individually, patients ticked items on a checklist of issues they would like help with, (e.g. meeting up, going for a walk, help with the groceries or transport to hospital). The App was shown to lower the barrier for patients to ask for help and enabled them to maintain relationships, suffer less loneliness, maintain a greater sense of control over their lives and maintain greater optimism about the future. There was also evidence that patients followed their medical regimes more precisely, experienced a greater sense of wellbeing during illness and made a faster recovery.

Similarly, the NHS Peninsula Cancer Alliance (Neck et al., 2020) reported beneficial effects from the use of video conferencing for psychotherapy and psychosocial interventions with cancer patients (but they also noted that adding weekly telecommunications to usual palliative care had led to worse reported symptom scores for advanced cancer, "possibly due to excess attention on symptoms" p.4).

7.7 'Seldom heard groups'

A small-scale review of patient perceptions of digital services by Healthwatch Rochdale (2020) that sought to engage with 'seldom heard groups' found that among the 63 people they engaged with the most frequent comments were about difficulty accessing digital means, including having a computer, smart phone, tablet and Wi-Fi or data availability, while the second most frequent comments were that the person needed a lot more help and support to use digital skills and technology and access to online booking services.

7.8 Monitoring the progress of digital inclusion in practice

The Leeds 'People's Voices Group' (chaired by Healthwatch Leeds and made up of representatives from: Forum Central, Leeds City Council, NHS Leeds Clinical Commissioning Group, Leeds Teaching Hospitals NHS Trust, Leeds Community Healthcare NHS Trust, Leeds and York Partnership NHS Foundation Trust, 100% Digital, academic and research organisations and wider third-sector partners) regularly take a 'temperature check' on how people in Leeds are experiencing digital inclusion and exclusion, gathering the voices of those facing the greatest health inequalities. Their 'Autumn CheckIn' (Healthwatch Leeds, 2020) reports findings collected via a 'Communities of Interest Network' made up of professionals and organisations working on behalf of: young people and care leavers; people with a physical or sensory impairment; people from black, Asian and minority ethnic communities including gypsies, travellers and Roma people; refugees, asylum seekers and migrants; single parents; people with a learning disability and/or Autism; unpaid carers; people who experience domestic violence; women/maternity service users; men's Health; people with mental health conditions; people with drug or alcohol issues; sex workers; homeless people; LGBT+ community members; older people; and people representing faith communities.

Respondents identified a list of initiatives they felt would support greater digital inclusion:

Carers	Long term affordable internet access
Young People	Services to remain flexible and not make the assumption that young people can access devices

Housing Associations	Grants to help redistribute funds to the people who need them
Sex Workers & Sexually Exploited Adults & Young People	Recognition that getting online is as much about having confidence as it is about having skills
Men	Peer-led support and training
Women	Private space in public venues where people can get online
Domestic violence & abuse	Schools to have enough technology to loan to young people
People with mental health conditions	Loan schemes to continue and to include guidance on data privacy and so on
Migrants, asylum seekers and refugees	Greater access to publicly available Wi-Fi
Homeless people	Group and one-to-one training
LGBT+	Public services to offer digital terminals in offices, with staff on hand to offer support
Gypsies & Travellers	Free Wi-Fi on local authority sites
People with learning disabilities	Device loan schemes to continue
Autistic people	Services should allow people to choose from a variety of online platforms when possible
Culturally diverse communities	Focus on people experiencing digital poverty
People with sensory impairment	There should be a regular focus on British Sign Language and other communications needs
Older people	Services' staff should be trained to support people during digital appointments

Community voices are an important part of decision making, they say, because "Leeds has committed to improving the health of the poorest the fastest". By starting with communities' lived experience and designing systems with them, "decision-makers put people at the heart of services". They encourage decision-makers to use the testimonies they gathered as a means of:

- Accessing up-to-date information about how different communities have experienced digital inclusion and exclusion.

- Integrating this information into the design of health and care services in a way that reflects People's Voices Group values of starting with, designing with, communicating with, working with and evaluating with people.
- Developing benchmarks for health and care services which take into account the needs and experiences of different community groups.

8   Some underlying principles of good practice in digital healthcare delivery

Echoing the observation in the Introduction in relation to the focus of the literature reviewed being primarily on the *positive* aspects of 'digital health', studies which draw out *principles* of good practice in digitally-mediated healthcare are also typically doing so in relation to the *technological effectiveness* of these modes of care for patients who *can or who are already accessing them* (considering elements such as user-friendliness or issues like interoperability etc), rather than identifying principles to guide greater inclusion for excluded groups.

For example, Connolly et al. (2020) highlight a number of features specifically in relation to Apps: they must have demonstrable advantages over alternative tools, be easy to navigate and be aligned with users' needs, skills and resources (see also Warren et al, 2019); the NHS Peninsula Cancer Alliance study (Neck et al, 2020) highlights the need to consider the effectiveness of the virtual delivery of appointments *across the cancer pathway*, from breaking bad news through discussing treatment options to offering health and wellbeing support etc; an IPPR report (Thomas et al., 2020), seeking to ensure the spread of innovation in the NHS, makes recommendations in terms of National Service Frameworks, regulation, value assessments, payment by outcomes, competency frameworks, the allocation of roles, training and peer support etc; and others similarly focus on *system design*, for example the 'toolkits' by Bakhai et al (2019) for using 'Online Consultations In Primary Care'; the CWTCH team's (2020) toolkit for the delivery of telepsychiatry; and NHS Digital First/Tollgate Medical Centre's (2020) Remote Clinical Triage Model.

Other examples of the delivery of 'digital healthcare', however, while focussing on implementation, *do* allow the identification of some underlying principles with potential to enhance digital inclusion, such as: taking a local approach; working with housing associations; free provision not only of skills training but of devices and sim cards; the use of peer mentors in training; not using exclusively online methods when researching digital exclusion; increasing the accessibility of the internet in public locations; and maintaining effective GP practice websites as sources of information and signposting.

Details of these follow:

- While the new data-driven approach to cancer treatment offers so much potential for personalised care, research by Borrows (2018) for 'Reform' echoes the need, highlighted earlier in this review, to build trust. If the NHS is to move to this data-driven model, Reform suggests a *local* approach, using the 19 Cancer Alliances to provide the platform for it, bringing together multiple actors across geographical areas to provide a more joined up approach to care, on the grounds that regional approaches have traditionally had more demonstrable success in obtaining trust and data sharing agreements due to closer proximity with the public and greater input into the use to which data are being put. Greater Manchester is cited as a Local Health and Care Record Exemplar, having been granted funding to improve data sharing across its health economy. On that basis, it launched 'DataWell', a software system that allows the secure exchange of patient electronic information across primary, community and secondary care.

Other local areas could look to build a similar software system, Borrows suggests, tailored to their local population needs.

- Greater Manchester is also cited in an International Longevity Centre report (2020) that describes how, since the start of the pandemic, local government employees have been providing free devices, SIM cards and WiFi to those who have do not have them, as well as helping disadvantaged groups to master digital skills.

- The Good Things Foundation (Piercy, 2019) documents initiatives undertaken in Thanet where a local housing association developed and delivered digital skills workshops to their older residents using peer mentors. The authors recommend that any personalised needs assessment for care and support in later life should encompass digital inclusion.

- A Healthwatch Coventry (2020) survey identified measures designed to expand access to those not currently using digital healthcare services, including skills training for patients and for staff and via accessible locations eg. making computers more publicly available, not only in libraries but in community pharmacies and GP practices.

- The fact that systems need to be *maintained* is highlighted by the 'check up' Healthwatch Peterborough conducted via its audit of GP websites throughout Cambridgeshire and Peterborough. It found that: half did not have the latest Covid-19 guidance for the public; just 22 out of 98 websites had links to information about changes to cancer services during the pandemic; it was difficult to find information about advocacy support for making a complaint; 72 sites had links to self-care information but some links did not work; less than half had information about the practice's Patient Participation Groups; and two out of three sites did not have good examples of accessible information for patients with sensory loss or learning disabilities. Healthwatch Camden (2020) also found significant variation in the offer between different GP practices. While examples of 'transactional access' were evident (e.g. online registration, Electronic Prescription Service, web accessibility and translation features, symptom checkers DoctorLink and e-Consult, and online consultations via email, LIVI-Video GP Service, WhatsApp, Skype and FaceTime), patient access to Summary Care Records and information about access had not improved since their 2015 audit.

The NHS 'Widening Digital Participation' programme draws out some of the principles underlying the kinds of practices reported here. The first phase of the programme focussed on a digital skills training approach; the second phase, running from 2017 to 2020 worked with 'Pathfinders' in local communities to develop 'digital health hubs', the prototype for which collaborated with the local council, CCG, medical practice, library, Healthwatch, Citizens Advice, disabled people's groups and selfcare groups. Run by local volunteers, it helped people with building digital confidence, signposting to local health activities, and motivating healthy behaviour change with particular digital inclusion challenges, including with homeless people, young carers, people with long term conditions, isolated older people, and people in social housing, to "take a fresh look at the barriers to digital inclusion and how they might be overcome" (Digital inclusion for health and social care, 2019 https://digital.nhs.uk/about-nhs-digital/our-work/digital-inclusion)

The programme describes itself as working to a co-design method of involving users (people), stakeholders (decision makers) and practitioners (frontline staff) in the process of design. It states:

"Whether you are designing digital products, patient pathways or both it is important that everyone affected has the opportunity to input into the process" and the report goes on to offer a set of co-design principles as a framework for those wishing to develop their own citizen involvement plans, as follows:

Design with people, not for them
The premise of co-design is including those who will be affected by decisions. They are the experts in their lives and know their world better than anyone else.

Go where the people are
Conversations are more open and honest when people feel comfortable and safe. Spend time where they spend time. Don't ask them to come to a formal building as it shifts the power dynamic. Consider your local community spaces.

Relationships not transactions
Health is a very emotive subject. People's relationships with professionals, peers, digital tools and their environment are unique to them and must be taken into account.

Work in the open
Share your learning. Share your work. Be transparent in your design decisions. Have the confidence to tell people why something has worked and why something hasn't. It will help others.

Understand underlying behaviour
Look beyond immediate causes to understand the many different factors underlying behaviour: personal and social, cultural and economic. Be conscious of the assumptions that you might make. Look beyond those that others might have made.

Do it now
We learn so much more by trying things. Get it out there and see what works and what doesn't. This will unearth things that you will have never considered before and make things better.

It is also important, they point out, to include variance in age, region, ethnicity as well as users with impairments (visual, motor, cognitive or hearing) and low digital confidence, posing the following questions to those developing greater digital participation:

- **Seldom heard voices**
  How could working with specific groups of users who might be regarded as 'hard to reach' or 'seldom heard' be helpful in ensuring the 'farthest away' are heard?
- **Experience of health services.**
  For wider-scale transformation work, such as interoperability and service transformation, it might be helpful to work with people and patients who are interacting with multiple health and care services frequently and over time - for example those with multiple long-term conditions.
- **Expert patient advisors**
  In some circumstances it'll be helpful to recruit patients to be members of your decision making or advisory groups and to play an 'expert patient advisor' role to challenge and inform rather than represent a specific view.

Many of the principles underlying the examples in this section (and themes raised in earlier sections) have been brought together in the final 'Widening Digital Participation' report (Stone et al., 2020) as key lessons/messages:

- **Recognise digital access and skills as a social determinant of health,** including intersectionalities between ethnicity, poverty, racial discrimination and poor health (improve national data on the links between digital inclusion, healthcare and outcomes to support this)
- **Co-design digital health services** – this involves recognising that digitalisation always needs to be seen as *part* of a solution, with patients being given a choice between digital, physical or a blend. Co-design of services should always include those who have low digital skills and face barriers to healthcare[3]
- Improve digital health literacy – this includes supporting people to navigate the health and wellbeing risks of internet and social media use as well as understanding how their health data is used
- **Develop digital health hubs to improve inclusion –** that are trusted and embedded in the community; respond to people's interests; reach poorly-served groups; build digital and health literacy together; support wider wellbeing as well as access to digitally-enabled healthcare – with the aim of building bridges between the community sector and health systems.
- **Take time to build trust and relationships with poorly-served groups** – this was an essential ingredient of successful outcomes, especially with people with severe and multiple disadvantages. Peer support from 'people like me' engaging in 'exploring together' and 'in my language' helped to build digital health literacy and confidence.
- **Harnessing and demonstrating the benefits to users themselves** – older people, carers, and those who may have developed low levels of trust in authority such as people dealing with homelessness, substance abuse and people seeking asylum can be helped to use both assistive technologies and the internet to find reliable sources of information.
- **Improve digital skills in the health and care workforce** – don't make assumptions about these; rather, recognise as valid concerns about service quality and job security and the need to build confidence and motivation for them too.
- **Embed digital inclusion in health, care and wellbeing strategies by building cross-sector bridges and networks**. The Leeds 'Dementia Pathfinder' is seen as an exemplar here.

On the basis of patient experiences, Healthwatch Shropshire (2020) also highlights how patient experiences (of both inclusion and exclusion) should be incorporated into service delivery. Concerned about the accelerated move to digital healthcare during the Covid crisis, they surveyed members of their rural county with its ageing population, where they were aware that not everyone has reliable access to the internet or a mobile phone signal or the necessary technology (e.g. a smart

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[3] There is a range of forums and networks across the NHS which aim to ensure patient and people's voices are incorporated in the planning and delivery of NHS services. They include a Youth Forum, an 'Older People's Sounding Board' contracted out to Age UK, a Learning Disability and Autism Advisory Group and Forum, a Gender Identity Network, a Commitment to Carers group, a Families/ parents forum, The nineteen Cancer Alliances and a Voluntary Community and Social Enterprise Health and Wellbeing Alliance, as well as a 'Citizens on the Margins' forum of people who often face marginalisation and higher health inequalities, such as those who use drugs, domestic abuse survivors, sex workers and homeless people. It is suggested that NHSX and NHS Digital teams work with these forums to ensure greater digital inclusion. The 'How we can support digital inclusion' report can be found here:

https://digital.nhs.uk/about-nhs-digital/our-work/digital-inclusion/supporting-digital-inclusion-locally

phone), or wants to use it. On the basis of their findings, they made a set of recommendations that can be regarded as guiding principles for more inclusive care:

- Inform the public that phone, video and online appointments are being used to triage patients and make sure people receive a face-to-face appointment if it is necessary and that it will be with the most appropriate professional, e.g. doctor, nurse, social worker.
- Fully implement the NHS Accessible Information Standard to make sure the communication needs and preferences of all people and their carers (if relevant) are known, recorded, shared across services and acted upon.
- Provide the public with clear information and instructions about how to set up and use the software needed to access video appointments and electronic consultations (e.g. e-Consult, the NHS App). This information should also be available in Easy-Read.
- Provide training for professionals about how to manage a phone or video consultation/meeting to make sure people have the opportunity to share any concerns and ask questions.
- Share the Healthwatch England guidance on 'Getting the most out of the virtual health and care experience'.
- The guidance, arising from collaboration with *National Voices* and Traverse, offers the following 'Top Tips' for the public and professionals:

Top tips for patients

- Ask for a timeslot for when your remote consultation will take place
- Let your healthcare provider know how you prefer to talk - by phone, video or in-person
- Find somewhere quiet and confidential and if this isn't possible or is tricky, make this clear when making your appointment
- Start with a phone call if you're not confident with video technology
- Ask for help if you need it and if possible, do a practice run with a friend
- Take some time to prepare in advance, consider what you need to say and key questions you would like to ask
- Ask your healthcare provider to summarise the next steps at the end of the appointment
- Remote consultations can be useful for routine appointments or ongoing care with a healthcare practitioner
- Not all appointments are suitable for remote consultations. If you would like to see someone in person, say so.

Top tips for health professionals

- Provide a precise time window for appointments
- Check that the person is in a confidential and safe place to have the phone or video call
- Understand the person's level of confidence using technology and give people a choice of how to communicate
- Proactively check what the patient needs, clarify what is happening next and who is responsible for the next stages of care
- Slow down the pace of the consultation, demonstrate active listening
- Use the chat function in video calls to make the appointment more interactive, share links to information or summarise next steps
- Don't ask people to provide information you already have access to
- Give guidance about how the appointment will work, offer demonstrations, provide an opportunity for a test run/provide some training
- Seek feedback about peoples' experiences and use this to improve the service

The guide is available at https://www.healthwatchshropshire.co.uk/advice-and-information/2020-08-03/getting-most-out-virtual-health-and-care-experience

<u>Healthwatch West Sussex (2020b) also offers a guide for health professionals to making digital consultations more inclusive:</u>

Appointments should be longer than normal as people need time to build a relationship as the normal welcoming social interactions that would happen when you enter the consultation room don't occur. Also need a timed appointment (like face-to-face) is preferable as a patient needs time to prepare.

Patients need time to describe the problem (this can be stressful, e.g. what if you don't get the words right?) With screens, you have to get them angled right so that you can show the problem. And things look different on the screens. This could be tricky, however, with the time constraints providers have. Friendly text/email before an appointment – a friendly hello and a guide to what to expect and what they expect would make things easier. This could include a hyperlink to a webpage with more information. This should include:

◦ Information - Who will be in the consultation as the patient can't see who's in the room.

◦ Reassurance - The only recording will be the notes on your medical records the clinician makes, and you can always get a copy of these – this is normal practice. We don't record our consultation in any other way.

◦ Advice - There can be delays in sound and images – we are sorry if this happens and please don't worry that this is anything other than delays because of the technology. Please feel free to ask us to repeat things, or to let us know if we've misunderstood something. If a question makes you feel uncomfortable, say, and we'll try asking for information differently.

◦ Requests - We'll ask you to keep your video on, as this helps us to better understand your medical concerns.

Clinicians should invite patients to say if they can't hear or see them clearly, and reassure that the questions being asked are to help them better understand a person's health and wellbeing needs. When making a digital appointment, ask if it would be helpful to upload photos ahead of the appointment, but it's important to explain who will see these and why. For example, to show an infected area. Review if there are any restrictions on under 18s making an appointment online, and if there are, review if this is appropriate.

The VCSE Health and Wellbeing Alliance have identified key actions to address the barriers digital healthcare can create for those at risk of exclusion:

• NHS England could work to ensure that all NHS health information, registration webpages and appointment webpages are accessible with low or no data costs. For example, in New Zealand, people can access the overnment's "Work and Income" website and online services for little or no cost, so even those who cannot afford wifi or to top up their mobile data can benefit from their online services.[4]
• NHS England and the VCSE Health and Wellbeing Alliance could develop guidance for healthcare services on how to ensure inclusion and accessibility of services while adopting an increasingly digital approach to service delivery. The VCSE Health and Wellbeing Alliance could co-produce this with people experiencing health inequalities.

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[4] https://www.workandincome.govt.nz/about-work-and-income/our-services/cheap-as-data/index.html

- NHS England and the VCSE Health and Wellbeing Alliance could develop standards for providing inclusive healthcare services while utilising digital tools.
- NHS England with input from the VCSE Health and Wellbeing Alliance could publish clear information on people's rights to access healthcare services and health information through non-digital means for those experiencing digital exclusion and information for people in general on what to expect from online consultations.
- NHS England should commit to collecting data to assess usage and experience of digitally enabled healthcare amongst populations experiencing inequalities and exclusion and commit to addressing any issues identified.
- Last but not least, NHS England should ensure face-to-face appointments remain an option for people, ensuring that people's preferences for the type of care they need are listened to and ensuring that digital does not become default.

Finally, Car et al (2020) offer guidelines to video consultations in primary and specialist care, as follows:

Guidance for clinicians

Before you begin
- Make sure you are conducting the video consultation in a private and quiet space
- Team—form a team that will support video consultations, from receptionists to IT support.
- Rehearse—test the video consultation equipment in a call with a member of the team before using it with a patient.
- Time of the consultation—video consultations can be scheduled in the same way as face-to-face or telephone appointments and some apps/platforms offer a virtual waiting room for the video consultation.
- Dress code—dress for video consultations as you would for clinic work, even if conducting them from home.
- Telephone number—obtain the patient's telephone number so you can call them if the video consultation gets interrupted or video quality deteriorates
- Home video consultations—if you are conducting the consultation from your home (or at a location other than the clinic), inform the patient and assure them that you have access to their electronic health records and all other resources needed; and that should the need arise, you will be able to arrange a face-to-face consultation in the clinic.
- Three-way communication—some video consultation apps enable three-way communication. Consider this when a carer or another healthcare professional (at a separate location) needs to be included.
- Guidance for patients—in advance of the appointment, share guidance for video consultations designed for them
- Free video calling apps—If you opt to use a popular video calling app, develop a protocol for its use and notify patients that using the app potentially has risks for privacy. In guidance for patients, include a disclaimer and warning about safe use, such as: "Do not use [named video calling app] for contacting your doctor or sending messages to clinic as these cannot be monitored and responded to in a safe manner. Instead, use online booking, call the practice, or if it is closed, use an out-of-hours provider."

Suggestions for remote physical examination
- The dynamic of remote physical examination will depend on the clinical problem and may resemble a face-to-face one, intertwined with history taking.

- The patient may need to partially undress. Carefully consider whether a remote intimate assessment is clinically necessary to provide care or reach a diagnosis in circumstances where it is not reasonable or appropriate to examine the patient in person, taking into account patient choice. The sense of privacy in relation to undressing will differ between people, so sensitively explore what the patient is comfortable to do in a video consultation and follow key principles for remote intimate clinical assessments outlined by the Royal College of Paediatrics and Child Health,. These are listed in the document Key principles for intimate clinical assessments undertaken remotely in response to COVID-19 published by Royal College of Paediatrics and Child Health,which apply to all age groups (https://www.gmc-uk.org//media/files/key_principles_for_intimate_clinical_assessments_undertaken_remotely_in_response_to_covid19_v1(1).pdf?la=en&hash=0A7816F6A8DA9240D7FCF5BDF28D5D98F1E7B194). [Accessed 28.1.21]
- A parent or carer can often help with video examinations. With a parent of a crying child with high fever you might ask: "Does the child have neck stiffness? Can she turn and move her head around and touch chin to her chest?" "Could you gently press on your child's ear—first left, then right? Does the child react as if they are in pain?" "Could you use your mobile phone's light to look into the child's mouth and tell me what you see?" "Could you take a photo of their throat and share it?"
- For visible complaints such as rashes, ask the patient to bring the area closer to the camera (if they use a smartphone, tablet, or computer's camera that can be moved). Examine a rash as you normally would but note that colours may look different, depending on the camera and lighting. If you can't see the rash clearly, consider arranging a face-to-face appointment instead.
- It may be helpful to examine for swollen legs, a skin lesion, or any other changes in visual appearance. Bear in mind possible practical challenges, particularly if the patient is using a fixed camera on a desktop computer.
- Examples of other aspects of examination may include assessment of vision, mobility, muscle strength, changes to appearance, and listening to the patient's cough. A patient may also be taught how to measure their oxygen saturation (if in possession of an oximeter), pulse rate, and respiratory rate, or asked to share an image of an affected body part (which typically has a higher resolution than a video consultation motion-image).

For long term conditions where video consultation is planned, discuss aspects of self-examination and how to use devices such as a thermometer, blood pressure monitor, glucose, peak flow, or international normalised ratio (INR) meter for self-examination or testing at home. Some patients may benefit from a face-to-face appointment (eg, with the practice nurse or healthcare assistant) to run through how to use these correctly.

Consider switching to a telephone, face-to-face consultation, or a home visit if:
- A telephone call will suffice, for example, for a brief follow-up call or for a patient you know well and is used to speaking with you on the phone
- Technology is not workable to the patient or they do not have sufficient digital literacy
- The patient does not have a smartphone or another video calling device and high-speed affordable internet connectivity (or data if using 4G). Both parties could experience technical difficulties with audio and video quality
- Communication is difficult because the patient is not able to hear or understand owing to hearing, linguistic, or cognitive problems
- You or the patient or carer become uncertain whether a video consultation is safe, such as when the patient reveals red flag symptoms or an important diagnosis or acute severe illness needs to be excluded with an examination.

- You need to discuss very serious issues or deliver difficult or bad news.

Guidance for patients on how to prepare for a video consultation:

Before the video consultation
- Test the device—such as smartphone, tablet (eg, iPad), laptop, or desktop computer, and check Internet connectivity—use broadband internet connection >1 Mbsor confirm the availability of a strong Wi-Fi/4G signal. If possible, use a wired connection.
- Power—check the device battery is fully charged or it is plugged in.
- Camera—adjust the position or angle so that you can be clearly seen by the doctor.
- Microphone and speakers—test them before the consultation.
- Room—find a private quiet space where the sound from the video consultation will not be overheard by others.
- Lighting—ensure the room is well lit. Cameras need more light than the human eye to produce a quality image. Use a broad light source with daylight, as this lessens shadows and reduces contrast. Position yourself towards the source of light, eg, if the window is the source of light, look towards it when looking into the camera. Avoid a high intensity light behind you as this darkens the image and the doctor may not be able to see you clearly.
- Appearance—check your appearance on the screen. Is the camera at the right distance from you so that the doctor can see you or the relevant body part for examination, and not just your face?
- Assistance—consider asking a family member or a carer to join you. They could help by taking notes of key actions or hold the smartphone during the examination. If the doctor will not be able to see the person who may be with you, let the doctor know they are present so that they could be involved in the consultation, if appropriate.
- Examination—Depending on the reason for the consultation (eg, a rash or swelling), consider wearing clothing that would enable the doctor to examine you by video.
- Measurements—if you have home devices such as a thermometer, blood pressure or blood glucose measurement monitor, do the measurements as needed before the consultation.
- Questions and notes—consider making a written list of concerns and queries before the consultation and record any important information about medical history such as allergies.
- Medication(s)—prepare the list of current medication(s) you are taking.
- Smartphone functions and features—familiarise yourself with the settings, functions, and features of your phone video consultation app, including the mute button or the video on/off button.

During the video consultation
- Introduction—introduce yourself, and inform the doctor at the start of the consultation of who else is with you if they are out of view.
- Audio and video—check the doctor can see and hear you clearly; otherwise a telephone consultation may be more appropriate.
- Notes—make notes of key points and actions.
- Questions—do ask questions and share any concerns you may have as you would in a face-to-face consultation.

NHS guides for clinicians and patients are also available here:
https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/08/C0638-nhs-vc-nhs-staff-quick-guide-a4.pdf

9   Conclusions

The subject of virtual and remote health exclusion brings together three enormous fields of study: Information and Communication Technology and its user/human interface; professional-lay relationships in the area of health and how these translate into practice for health professionals from different specialties and patients from diverse backgrounds, living different kinds of lives and with different needs; and health inequalities and their determinants. When they intersect in practice, there is a huge amount of learning to capture, especially under the conditions of a pandemic when the pace of 'implementation' of virtual and remote forms of health service delivery outstrip the capacity of participants to undertake/process/translate that learning. We might add in to the mix two other factors: the years of underfunding in public services that Professor Sir Michael Marmot highlights, which have exacerbated the social determinants of health inequalities; and the way 'experts'/research have been valued/funded (until recent events have led to rapid re-evaluations), which has inevitably impacted on the methods, scale and quality of *some* research studies. It is perhaps not surprising therefore that this review does not paint a very encouraging picture of the current state of play in terms of the vicious cycle between health in/equalities; virtual and remote health; and digital health exclusion.

Helen Milner, Chief Executive of the Good Things Foundation pointed out the clear links between digital exclusion and social exclusion; between social exclusion and poverty; and between poverty and health inequalities, in a recent interview with *The Lancet Digital Health* (Watts, 2020). Health inequality has worsened in the past 10 years and digital exclusion plays into that trend, as Professor Simeon Yates, joint-chair of the UK Government Department of Digital, Culture, Media and Sport Working Group on Digital Inclusion and Skills recognised. He also commented that when it comes to tackling exclusion, "We do now seem to have hit the hard-to-reach [sector]."

That said, he thinks that COVID-19 will at least push exclusion up the political agenda. Helen Milner also senses "an overall greater awareness that digital inclusion is important" but is less certain that this will be followed by more funds and more action. Her hope is that if the digital divide's many consequences are now seen to impinge on more areas of life than had previously been realised, the pressure for action will be correspondingly greater. We can only hope, for the health of the significant sections of society identified in this report as currently excluded from remote and virtual healthcare, that she is right.

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Acknowledgements

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National Voices

National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 160 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

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