Cognitive Accessibility for Digital Health:
a preliminary study
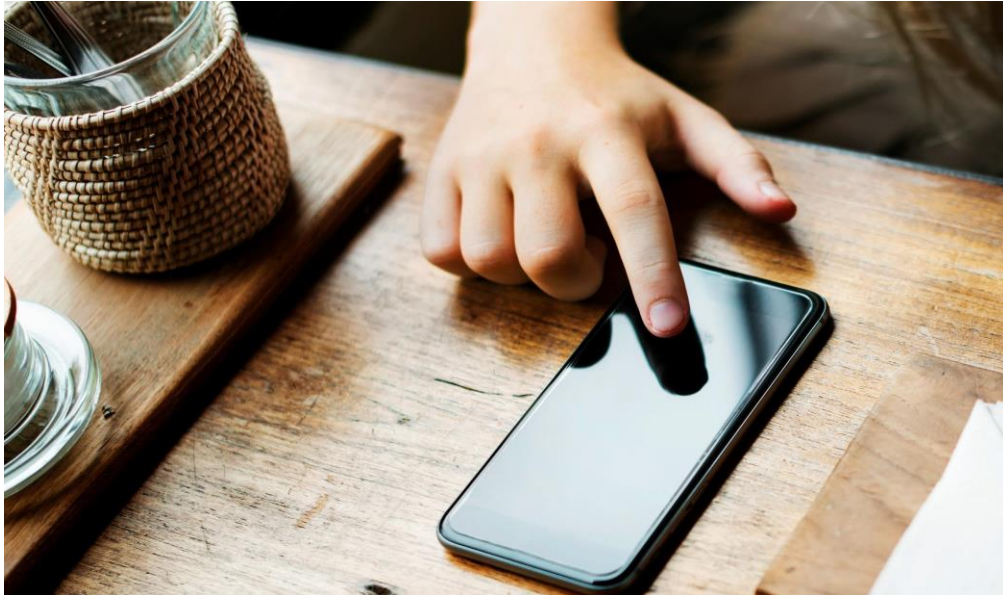
Image shows a person's index finger touching the screen of a device, resting on a wooden table.

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Summary

According to the 2020 Lloyd's Bank Digital Index [1], 16% of the UK population are unable to use the internet and their devices by themselves, and many more struggle to access and make the most of digital health products services. It's not necessarily who we might expect either: 44% of those offline are under the age of 60, and the reasons for this are not yet fully explored.

This preliminary study was devised using service design and user centric approaches, and utilises rapid ethnography to capture and examine the experiences of people using digital health tools and services.

The goal of this study is to explore these questions:

- Are cognitive impairments a significant barrier or hindrance to those using digital healthcare?

- Are cognitive accessibility factors well understood and addressed yet?

- If not, why, and what can we do about this?

Key themes and insights are outlined and placed in social, cultural and legal context.

A representative group of existing cognitive accessibility guidelines are placed under initial review, a draft evaluation framework established, and next steps identified.

Note on accessibility

This document aims to demonstrate some useful accessibility measures, such as clear unambiguous speech, widely spaced lines of text, and image captions. It has not been possible to apply all of the principles of cognitive accessibility due to limited scope and resources.

KEYWORDS: USER EXPERIENCE, SERVICE DESIGN, HEALTHCARE, SOCIAL CARE, HEALTH POLICY, DIGITAL INCLUSION, INNOVATION, COGNITION, DISABILITY AND LIVED EXPERIENCE, AUTISM, COGNITION, HUMAN RIGHTS.

[1]https://www.lloydsbank.com/banking-with-us/whats-happening/consumer-digital-index/key-findings.html

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Context

Image shows two older women seated at a table at home, smiling and discussing using a device.

Everyone's good health and wellbeing depends on being able to access the right medical attention and care at the right time.

Not only do people need to access critical information, but they now also need to be able to identify and communicate their concerns and experiences effectively.

Currently, many people struggle with this, either because they have disabilities, or because of reduced capacity or cultural barriers… or because they simply can't use digital services easily.

Multi-morbidities and complex health issues are on the rise, costing the NHS £4.3bn in 2013. During 2020, the costs of unaddressed exclusions were made fully evident by the disproportionately high numbers of disabled and vulnerable people who lost their lives to COVID-19.

One considerable factor is the lack of adequate accessibility and inclusion measures, meaning many people find it hard to access the services they need when they need them, and are left out and left behind, at great social and individual cost.

As healthcare digitises further and moves to integrated care systems, more attention is now being paid to addressing such barriers, yet efforts are often fragmented or incomplete. These barriers may include factors such as:

- personal issues, such as lack of motivation, fear, reluctance
- technical issues: lack of suitable device, lack of service
- medical issues: limited pathways or unhelpful assumptions
- social or cultural issues: discrimination, bias and other exclusions
- knowledge: lack of a skill that could be learnt or self-taught
- capacity : impairments and limitations arising from disability or poor health

Disability Impairments are often a combination of:

- Visual/ perceptual
- Dexterity / physical
- Cognitive/ procedural
- Social/ cultural
- Sensory / awareness

Underlying health issues may also play a role in some impairments.

The following can be just as disabling, or exclusionary

- Negative perceptions about disability and disabled people
- Ableism - assumption about what people can and cannot do
- Lack of effective guidance or support
- Compartmentalising and limited framing
- Discrimination and bias - explicit or implicit

The burden for countering these often falls to the individual, and is a considerable cognitive, practical and emotional load, which not everyone has the capacity and support to bear.

This image shows a seated woman with her hand covering her face. Her body language shows that she is upset and not coping.

Cognitive Accessibility

Cognitive accessibility measures are often only considered in the context of services for autistic people, and for those with learning disabilities or forms dementia, yet cognitive barriers can be faced by anyone at any time.

While a great deal of effort is now going into the development and production of resources for people with learning disabilities, most common cognitive issues are not properly considered, and adequate measures rarely put in place.

This is highly problematic, as alongside better recognised issues such as dementia, head injuries and neurological disorders, conditions such as menopause, heart disease, head injury, and gut disorders can all impair cognition. Stress, some medications, and of course substance abuse can also lead to significant impairments, which the individual may not even be aware of.

Cognitive Support is often needed to overcome:

- broken 'journeys'
- too many steps to follow
- unreliable technology or interactions
- overly complex processes and procedures
- use of medical jargon and acronyms
- unclear, treatment plans, provision and pathways
- repetitive, intrusive or highly irrelevant requests
- services concepts and options that don't quite fit or are poorly framed
- not having regular access to the internet due to practical offline barriers
- lack of appropriate, accessible online support or help

There is a common assumption that it's OK to 'muddle through' things especially where people are not confident in being able to complete a task or process successfully. Muddling through is not ideal in any situation but is unacceptable when people's health and wellbeing is at stake.

Given how critical it is that people can access digital health services, a surprising number of issues are going unaddressed or even unresearched.

Why is this the case, and what can be done to address this?

The flip side of the current emphasis on self-reliance is that people often feel ashamed to ask for help, or undeserving of it should they get lost, or stuck. Offering help normalises support and takes away the stigma and negative aspects of asking for assistance, and yet this just does not happen enough yet.

Common models and behavioural assumptions state that if services are not used fully and people don't keep up with the suggested programmes or activities, it is because they lack motivation, or the will to 'engage' and be in 'compliance'.

User research and anecdotal reports indicate that in actuality, people may desperately want to participate but may lack capacity, the ability to focus or the support they need to do take part.

User experience for digital healthcare is becoming more and more sophisticated, going beyond the appearance of products and services, to considering the entire journey, although in a limited way.

There are many well researched evidence-based 'pathways' and 'protocols' for clinical and medical services, but the guidelines and 'patterns' for full accessibility of services are much less well defined.

Furthermore, many of the measures needed to address such barriers can't be delivered digitally, at least not yet, so human intervention will still need to be a key part of the solution.

Despite this being such a critical issue, there is a dire lack of research into the full range of cognitive barriers that people face throughout the complete end to end user journey.

There are many resources available to help create accessible content, and cognitive accessibility for web services has just reached a significant milestone with the launch of [revised standards from the W3C Web Accessibility Initiative (WAI).](#) [2]

But in order to ensure full cognitive accessibility, digital innovators and those commissioning services need clear guidance in a wider range of contexts, and to have access to the right insights and data too.

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[2] https://www.w3.org/WAI/cognitive/#cognitive-accessibility-in-w3c-standards

There is a list of cognitive accessibility resources and information at the end of this document, however it is unlikely that any one specific resource or set of guidelines will cover all the relevant aspects needed.

This is why the assessment framework outlined in section 2 is so necessary. Making a systematic comparison helps establish which sets of guidelines might be most appropriate, and what might yet need to be researched.

Working out the exact accessibility measures needed to ensure universal access to a service is not something that can or should be done by using a tick box list.

Existing guidelines are however a good place to start, and make a firm basis for further consultation, verification and co-production.

Image shows a diverse group of people seated around a meeting room table, in discussion.

Navigating the maze

Most digital health and care services are based around 'gold standard' treatment and protocols. This approach works well for specific known conditions, yet is a huge barrier where people have multiple, complex or less understood issues, and struggle to fit their circumstances to the product or service.

Being on the wrong treatment plan or pathway is a clinical barrier, disempowers and erodes people's trust in medical systems and staff. Services that are such a poor fit place the individual in the position of having to find workarounds to attempt to have their actual needs met.

These situations are especially hard for people with cognitive impairments to navigate and to assert their needs, however motivated they may be to obtain the help, treatment or care on offer.

For those that have survived COVID-19, complications can be serious, and difficult to diagnose and treat. As with other complex conditions and disabilities, it can be hard to work out what is going on, and to communicate concerns.

As pointed out in this recent BMA article,[3] many of the symptoms of 'Long COVID' appear to relate to post viral syndromes. There are also strong indications of causal links to a whole range of autoimmune or autonomic conditions and hidden disabilities.

All of these conditions can bring problems with focus, attention and capacity, which digital health needs to acknowledge and accommodate if it is to meet the needs for inclusive remote services and to ensure the gathering of critical complex data.

Addressing the data gap

Diversity and inclusion in health and social care is now being even more seriously than before. In the UK, the NHS are now taking a more structured, and transformative view and seeking to apply more user led systemic approaches and solutions.

New models of integrated health and social care are being built around insights gathered from lived experience, and expert patients, and a more participatory, design led approach is emerging.

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[3] https://www.bma.org.uk/news-and-opinion/long-covid-we-ve-been-here-before

Yet if this transformational work is still based on current models of behaviour and assumptions about how people interact with technology, and misses out that people need support and assistance, then it is still excluding people by design, which is unacceptable - and in breach of equality law too.

People can be so completely excluded from a service, that they never even book in or sign up. They may also lack the agency capacity and support to complain about this, or even to recognize that they have been left out. This is unacceptable.

If the data that is used to scope and plan new services comes from services that are not accessible and inclusive, then the picture will be incomplete, and the bias and exclusions carried forward.

In order to map these hidden exclusions, we have to apply the missing accessibility and inclusion principles and measures to our research, and actively support and engage participants to help us do this.

Engaging more directly with service users and people with lived experience, enables a deeper and more look at what is happening now, and also uncovers what issues may lie on the horizon too.

This study aims to do just that, and to:

- Expose and evidence lived experience narratives and relevant insights
- Highlight measures that will address these oversimplifications and bias
- Present and reframe these issues in a way that will support user experience designers and innovators to improve services for all.
- Evidence best practice in user research and design anthropology

So what are the kinds of challenges that need to be overcome, and where do we start?

Part I Survey

Survey design

In order to be accessible and inclusive, the digital healthcare industry must closely examine how and why people are not using products and services, and fully explore and address the cognitive, practical, logistical and cultural barriers they face.

Profound accessibility issues, assumptions about individual capacity and general oversimplifications must be recognised and measures put in place - ideally through user research co-design and co-production, and by the industry working together as a whole.

This initial study has been designed to

- validate these arguments and the confirm the need behind them
- generate data that will help explore and map these issues
- gather people's views in both a structured and unstructured format
- consider person centred innovation and approaches
- offer insights and recommendations for action
- prompt and enable further analysis and research

This survey ran from 29 December 2020 to 29 January 2021, and was designed to help us understand more about what tools and services participants need, and how to support them. The participants' responses are confidential, and data or insights from this survey fully anonymised.

The majority of the 232 participants were recruited via a popular competition site and the attraction of a low value prize draw, creating an interesting diversity of reach, and spread of responses. Other participants were recruited through Facebook groups supporting those with long covid, and from people in our immediate circle of contact.

We chose to not make the responses compulsory, or a condition of entering the prize draw.

Therefore it could be proposed that motivation to complete the survey fully has come as much from the desire to share experiences and to be heard, as to win a prize. Future surveys could reflect and capture this distinction more carefully.

The survey was semi-structured. Questions were stated in plain easy-to-understand terms, and the response options were designed to prompt responses without suggesting them. Almost every question gave people the option of responding quickly using tick boxes or using their own words in the 'other' option.

We avoided using grids of tick boxes for options and permutations because these are complex, raise accessibility issues and can be challenging for many people to understand.

We also wanted to encourage the submission of data using people's personal narratives, yet in a structured way.

Survey Responses

Participant profile

- Average age of respondent: 41
- Most live in the UK
- They are technology literate
- Most completed the form fully
- 97% of participants use some form of digital health

COVID-19 status / Post COVID

- 6% are uncertain about whether they have had COVID-19 AND whether they have long COVID
- 56% are uncertain about whether they have had COVID-19 OR if they have long COVID.

What tech are people using?

Symptom tracker or diary	20.7%
Symptom tracker or diary linked to a specific device	3.4%
Screening questionnaires and surveys	19.4%
Self -management tools for a specific condition	11.2%
AI or chatbot support or coaching	3.0%
Telephone / remote Doctor	28.4%
Remote 1-2-1 health coaching	1.3%
Remote 1-2-1 health advocacy	11.7%
Using 3 or more kinds of digital health.	6%

Where do people go to find health information?

GP/doctors	14.6%
Google	14.6%
Online	3.5%
Offline	3.5%
Forums / Groups	3.5%
Facebook	4.7%
Patient Groups	1.2%
Friends / Colleagues	13.5%
Family	18.1%
111	1.8%
NHS website	18.7%
Other Professionals	2.3%

There was a large range of other sources that people report solely relying on: magazines, Boots the chemist, Instagram friends, Quora, Mumsnet, Twitter, 'WhatsApp group with fellow parents', Radio 4, WebMD and in one case: Pubmed, Lancet and Medonline.

In summary, many people are still speaking to their GP, or going directly to reputable sources but a surprising number of people are reliant on each other to find information and to work out if it is relevant to them, or if guidance is appropriate.

"I turn to family and friends first, rarely Google search as I find it overwhelming!

"Doctor Google before I bother my GP"

"I attend a 'large' health centre with a number of Doctors but there is one who I usually see who has been VERY helpful at understanding what I have said to her on various occasions and explaining the situation to me (in terms I can understand!). I am also reasonably confident about looking things up on line - and reading between the lines of some of the stuff on line. I also have a step-daughter who has been a Nurse (albeit Mental Health Nurse) for about 25 years and who is reasonably good at putting things in plain English and sometimes saying whether there is anything to actually see the Dr about."

I just talk to the wall normally, I get more sense that way.

There is a clear demand for services that signpost key information, and that help people evaluate it - and in an individualised context. And that reaches those who feel alienated or overwhelmed.

Would you say that you are confident in using digital health services?

Response	Number of people	%
Definitely	29	12.5%
Probably	64	27.6%
Not sure	61	26.3%
Probably not	29	12.5%
Definitely Not	18	7.8%
no response	31	13.4%

Confidence ratio** here is 4.95/10

Do any of the following affect how you use digital health services?

brain fog	25%
memory issues	18%

hard to focus	23%
confusion or indecision	16%
too much pain or nausea	7%
too tired	41%
It's just too difficult	13%
I need someone to help me	10%
People reporting four or more issues	3%

Digital Health narratives - in participants own words:

"A diary is most useful as symptoms are subject to change even throughout the same day and can easily show these symptoms to doctors

"I like screening services that tell you who is best to contact based on my symptoms, or being able to talk to a doctor or nurse about my symptoms"

"Very happy, having a easy questionnaire to work out what is wrong with me helps me decide if I need to see a doctor or if it's something that I can manage myself so I'm not taking up the doctors time as it can help someone else who really needs to see a doctor use that time."

"Very useful for minor ailments and those where you are pretty sure yourself what the problem is. Also very good for reviewing conditions.

"I'm very happy. If I were to improve anything I would suggest improving the interface of the applications."
I don't think it would be as good for serious problems of those where you have no idea what the problem is"

"i believe that if someone has dealt with alot of trauma previous to contact with doctor a robot will not do or automation. someone with no will to go on or genuinely in bits after weeks of being awake wont function like an everyday person, i,e paranoia , dissatatchment.(sic) one to one with a pro is

vital or they could be looking for that rope while the automated system cant grasp a welsh accent. all in all, good job on a whole but im seeing alot of people who aren't used to being on their own suffer"

"I don't have a device that's compatible with some apps"

"Absolute lack of confidence in a good outcome."

Part II: Cognitive accessibility guidance assessment framework

Accessing and utilising digital tools can require the successful completion of many steps, from the sign up process, through to logging in, filling out forms and many more complex interactions.

Every step has to be carried out successfully. A single misstep can break the journey, resulting in lost opportunities, lost data or leading to the person abandoning the service.

To be effective and ensure that everyone's needs are met, accessibility guidelines must be comprehensive, functional and most critically, shaped by the people they serve.

While not every step is under the designer's control, or necessarily online, every step in a particular event, process or programme needs to be considered and taken into account.

So what guidance is out there, and how comprehensive is it?

We reviewed cognitive accessibility guidance from a range of institutional and state sources, as well as a sample of smaller community and lived experience groups.

We then took key data points from this review to create a draft assessment framework to aid in the comparison and evaluation of these sets of guidance. The intention is to scope and review existing literature and not to criticise, rank or to single out any one individual resource.

The assessment framework provides a strategic view, and one that is relatively easy to use and accessible both to those who implement accessibility guidance, and to the very people they aim to serve.

This framework is designed to provide a useful overview now and enable the effective monitoring of future developments and measures in the area of cognitive accessibility.

It takes a multifactorial slice through key aspects of these resources, and in correspondence to the areas of concern as laid out in the criteria below.

[The latest version of the framework, along with the analysis carried out so far may be found here](). [4]

[4] https://github.com/lucykwills/cognitive

This document and related resources will be uploaded to this GitHub instance. Subsequent updates will appear there. This research is open and designed for collective working. Potential contributors and collaborators should request access there too, or by emailing hello@globefoxhealth.com.

What have we observed so far?

The guidelines we have looked at are making laudable attempts to address some of the bias shown by digital health innovators and by innovation culture as a whole.

However, there is still an overall tendency to:

- Focus mainly on website and app accessibility
- Underplay the importance of clear processes, plain language and offering a range of access options at the same time.
- Assume that specific diagnoses or conditions have set capabilities and impairments, or that cognitive issues happen in isolation
- Fail to recognise the executive function and procedural capacities needed to complete tasks and end to end processes may be limited.
- Miss out that impairments are often made worse when combined with social and cultural factors, such as the lack of support, stress or trauma, or other discriminations.

It is the view of the authors of this study that the most critical omission is in the overall framing of cognitive accessibility work.

It needs to be better put forward and understood that cognitive impairments may occur to anyone at any time, so that accessibility is not simply a special measure for a small group of people but a larger scale endeavour that will benefit everyone.

Part III Horizons

Conclusions

Cognitive accessibility has clearly been reported to be a critical issue and significant barrier for our survey respondents. Though we cannot claim that this group is fully representative, this does tally with the existing data points - even though some of these have had to be inferred, due to the lack of precise data.

New digital health systems and processes are being implemented rapidly, and yet often with insufficient oversight. There is not enough attention paid to the full implications and consequences of these changes, both in preventing access and in perpetuating bias and exclusions.

There is a clear and urgent need for further user research and accessibility work and for research to accurately map the prevalence of cognitive impairments, and especially how they affect people in a healthcare context.

This research must actively address complex or intersections of exclusion, by seeking out and supporting those people who would otherwise be missed. Efforts to increase access to health and social care must take into account the day-to-day challenges many people face, and especially the difficulty in accessing appropriate support.

Health and care systems must also build in support for people to speak up when things are not right and to enable everyone to play an active role in service improvement.

Disabled people are demanding a greater say in how and even which services are developed, and at a much more strategic level. Understanding cognitive accessibility and user research in depth is important but so is listening the views and experiences of those using the service.

The key finding of our cognitive accessibility guidance review is that there is a huge disparity in depth and detail between the sets of guidance, especially across sectors.

Furthermore, the definitions of cognitive impairments are inconsistent and tend to derive more from the impacts of known learning disabilities and differences than of a full range of impairments. Many factors can affect cognition, and assumptions that may limit efforts should be revisited.

When designing digital health services, the entire user journey and personal experience must be considered - online and offline. Even the most well considered digital tool is inaccessible if all of the required steps are not well supported.

These issues are better recognised by the games industry, with an extensive cognitive accessibility framework which other digital industries would do well to adopt, adapt and build upon. The support needs of neurodivergent people and those with cognitive impairments need to be considered and supported more often across all industries.

Beyond Disability

The social model of disability emphasises that it is society that disables the person through the lack of support, negative bias and discrimination.

Just because people are impaired does not mean that they will lack capacity when supported, or have any less right to contribute to, or even design the services that are being made for them.

Many people with cognitive impairments or differences would not consider themselves to be disabled, or even want to. Other people's needs go unrecognised due to the lack of resources and opportunities to gain an appropriate assessment, let alone the level of diagnosis that can be required before support is given.

This study has been led by an autistic dyslexic dyspraxic researcher, and much of it has been informed by conversations with other neurodiverse people.

Autistic people remain frustrated by much of the framing of research and design of services and want to be more involved in, or even leading the user research. More must be done to enable nurture and progress researchers, designers and innovators who are working from lived experience and deep insight.

We also need to consider people who are temporarily impaired or experience sickness, stress or traumatic life events. Indeed, any of us may have a day where we struggle to process or take on board information, and if we fail, this may lead to taking inappropriate action or making decisions that may not be in our best interest.

Regulatory and cultural changes

The Equality Act 2010 places a statutory duty on those providing public and commercial health and social care services to take all reasonable steps to ensure that people are not excluded.

Sadly, this is often seen as the duty to provide some adjustments to some people, and in some contexts, and often only on request, which can be very stressful and demeaning to those who are in need of them. There is a definite hierarchy of access, based on demographics, capacity and agency, health status or diagnosis or the obviousness of the impairment or need. This is not what current law and commitments to diversity and inclusion require.

Validation, effectiveness and impact should be the deciding factors as to whether accessibility measures are put in place, not arbitrary prioritisations. Furthermore, even measures that may not have an immediate or obvious effect should still be fully researched, scoped and evaluated, and not dismissed out of hand.

As so many parts of healthcare are looking to digitise services there is a significant opportunity to embed accessibility by default. Data that is being gathered about discrimination, diversity and bias should also include who is being left out, how, where, and why.

This is especially critical in health and social care, where the consequences of exclusion lead to shorter lives and reduced quality of life, and the failing of the social contract between state and individual.

The health and social care sector must break out of accessibility silos, and think more widely about cognitive issues, and the need for social and other support to ensure access and participation. This must be addressed If the NHS is to fulfil the objectives of the NHS Long Term Plan, [5] and for the sector as whole to meet the commitments and demands of integrated and personalized care.

Many laws and regulations around the world mandate that critical services such as health care must be accessible to all, yet for many reasons such laws are rarely enforced. Good digital healthcare must seek to ensure access for all, not just implement a regulatory minimum. Too many people have been left behind for too long.

[5] https://www.longtermplan.nhs.uk/online-version/

Bibliography and further reading

This is a preliminary list, further resources will be added and the whole list fully cited in due course. This list is currently in alphabetical order, by title.

Where no date is given, the resource is either undated or under active maintenance. Last updated indicates the last update before the time the resource was accessed.

Resource	Author, date
10 Small Design Mistakes We Still Make	Eugen Eşanu 2018
A list of cognitive biases to watch out for in user research	Daniel Schwarz 2021
Accessibility and Beyond: Designing Consumer Health IT for Disabled Individuals (Virginia) |	Rupa Valdez, PhD et al 2018
Accessible communication formats	UK Department of Work and Pensions / Office for disability issues Last updated 2020
Content- What content designers, writers and editors need to do to make digital services accessible.	NHS Service design manual Last updated 2019
Design Principles	Jeremy Keith

Digital Accessibility: a brief landscaping	Citizens Online
	2015
Digital Health Technologies to Promote Lifestyle Change and Adherence	Numan Khan MD, Francoise A. Marvel MD, Jane Wang BS & Seth S. Martin MD, MHS
	2017
Digital inclusion for health and social care	NHS Digital
	Last updated 2019
Digital Inclusion in Mental Health – A Guide to Help Increase Choice and Improve Access to Digital Mental Health Services	Dania Hanif
	2020
Digital Technology Assessment Criteria (DTAC) For health and social care	NHSx
	Last updated 2020
Game Accessibility Guidelines	List of contributors
How to Make Information Accessible - a guide to Easy Read documents	Change People
	2016
https://www.citizensonline.org.uk/digital-exclusion-in-population-screening-programmes/	Citizens Online
	2020
Independent SAGE report on Long COVID	Independent Sage

	Last updated 2021
[Lloyds Bank UK Consumer Digital Index](#)	Lloyds Bank, 2020
[Locked In or Locked Out - COVID-19 Remote Technology research project.](#)	Shaping Our Lives 2021
[Making Content Usable for People with Cognitive and Learning Disabilities](#)	W3C Web Accessibility Initiative (WAI) Last updated 2021
[Multi-Factor Authentication Is Inaccessible](#)	Devon Price 2019
[Overcoming Barriers to Adoption of Digital Health Tools for Diabetes](#)	David C. Klonoff MD, FACP, FRCPE, David Kerr, MD, FRCPE 2017
[Publishing accessible documents](#)	Government Digital service Last updated 2020
[The State of Digital Accessibility in Healthcare](#)	Essential Accessibility 2015
[The stigma is real for people living with long covid](#)	Marija Pantelic and Nisreen Alwan 2021

[Tips for effective accessibility research](#)   NHS Blog- Ashley Wheat.
2019

[Visual supports for communication.](#)   National Autistic Society

[Voice Principles | Clearleft](#)   Ben Sauer @bensauer

[What all NHS services need to do about accessibility](#)   NHS Service Manual,
Last updated 2019

[What is Makaton?](#)   Makaton

[What is Neurodiversity?](#)   Autistik

[Xbox Accessibility Guidelines V2.0](#)   Microsoft,
Last updated 2021

About the researchers

Lucy Wills MA RSA is a technologist, designer and independent researcher, and the founder of Globefox Health, a patient-led healthcare service developing health and well-being assessments and self-management for rare and complex disorders, including Long Covid.

She is also the Lived Experience Alliance Manager at Disability Rights UK, working to uncover, communicate and highlight the barriers and challenges that many disabled people experience in accessing healthcare. Lucy took part in recent critical Department of Health and Social Care / Health and Wellbeing Alliance consultations and provided collated lived experience insights, significant domain knowledge and design expertise.

She also reviewed accessible materials for the NHS Vaccination programme and was a key resource for the research and development of accessibility guidelines for NHS Test and Trace. She also undertook high level policy work, and represented disabled people's needs and views at COVID-19 emergency meetings and briefings, and in critical working groups.

She also contributes to the work of AI for Good, We and AI and Citizens Online. A previous research report, 'Design Values' examined critical success factors for design through the needs of the designer and was published by Innovate UK.

Ruth Ivimey-Cook BEng trained over 30 years ago in both electronics and software engineering, and has since had an intentionally varied career, including 20 years on the review committee of a parallel processing conference, and working with the founding team of the biology Journal eLife. She is also the editor of a quarterly 48-page colour magazine. In her personal life she has experienced several of the conditions mentioned in this report.

Tim Bailey has been working with Globefox Health for 18 months, developing the operational processes and contributing to the strategic development of the company. With a BSc in biomedical sciences and an MSc in business, he also brings experience of large data set analysis, digital operations to the organisation.

Tim has previously written about research evaluation, regulatory environments for new technology and managing digital technologies

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Globefox Health is creating inclusive digital health services that enable and support everyone to understand and communicate health concerns more effectively.

This work is based on over 5 years of research into under-recognised health issues and the reasons why they are so often missed.

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