

# **PROJECT REPORT**

# A digital inclusion framework for health and care: Sussex

A collaboration between NHS Sussex and the University of Sussex

14/12/2022

# **Executive Summary September 2022**

This report contains a summary of the development of a digital inclusion framework for health and care developed in collaboration between NHS Sussex and the University of Sussex; a summary of digital exclusion and its impact on populations, digital health and care, and health inequalities; a digital inclusion framework for health and care based on the service users journey with digital health and care; a design/assessment tool; and recommendations for mitigating against digital inclusion in health and care.

The content of this report can be used to support the development of a digital inclusion strategy for health and care in Sussex, and application of the framework will now be tested across various digital health and care workstreams.

With thanks to colleagues across NHS Sussex, researchers at the University of Sussex, and wider stakeholders involved in the development of this framework.

Amendments to version 1.2 1	0/22	
14/12/22 New Version 1.3 FINAL 12/22	<ol> <li>Corrected typo on assessment tool (changed from 'to mitigate against digital inclusion', to 'mitigate digital exclusion' in all recommendation boxes</li> <li>Added updated image of enablers and barriers (cogs)</li> <li>Added updated image of framework</li> </ol>	K Sykes

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# A Digital Inclusion Framework for Health and Care

In response to the rapid digital transformation in health and care, particularly since COVID-19, a digital inclusion framework for health and care has been developed in collaboration between NHS Sussex and the University of Sussex and with support from Kent Surrey Sussex Academic Health Science Network following a person-centred design process.

Relevant policy and evidence in relation to enablers and barriers to digital inclusion, and local health and care system engagement findings and feedback have been used to develop and sense test this digital inclusion framework for health and care which considers digital engagement from a health and care service user's perspective.

This report summarises the evidence used to inform the framework, introduces the digital inclusion framework for health and care, and provides recommendations and a design tool that will support evidence based, practical design of inclusive digital health and care pathways that mitigate against health inequalities including digital exclusion.

The overall aim of this health and care digital inclusion framework is to enable everyone that can benefit from digital health and care to do so, when they need to, and to ensure that inaccessible pathways and technologies are not creating barriers and causing un-engagement in digital health and care.

# Digital Transformation in Health and Care

Digital health and care has the potential to not only empower people to manage their health and care better, but also improve clinical outcomes, effectiveness and efficiency across the health and social care system. A primary objective in the digital transformation of health and care is to empower people to better manage their own health and wellbeing, and to provide improved health and care out-of-hospital including in people's homes when that is appropriate.

Current (public facing) digital transformation in health and care includes:

- Digital products that provide healthcare advice, support people to live well, and/or manage long term conditions.
- Digital products that allow people to book GP and hospital appointments, order repeat prescriptions, and have sight of their medical information and test results.

- Technology that supports sharing of information, treatment assessments, virtual consultations, wellbeing checks, and health and care communication.
- Virtual health monitoring technology such as measuring vital signs at home; and virtual wards- providing more complex care at home to either avoid admissions or enable earlier discharge where that benefits the individual.

Yet, despite its potential benefits, the introduction of digital health and care solutions risks excluding the most vulnerable and highest need population(s) and perpetuating or exacerbating health inequalities. This includes populations that may most benefit from digital health and care and ultimately find this a more accessible way to access health and care but are currently excluded through challenges presented by service and technology design. Indeed, the wide variety of digital solutions already in place to access and interact with health and care services, and lack of integration across these solutions, can mean that some people are already excluded from accessing digital first, or digital only health and care.

Inclusive digital health and care is essential if health and care is to deliver on its commitment to digital transformation (NHS Digital); meet the goals of health and social care policy (NHSE), (gov.uk); deliver national and local health and care priorities, improve health and care outcomes, enable people to better manage their health and care, and reduce health inequalities (NHSE); (gov.uk). Digital inclusion is essential if the health and care system is to deliver exceptional health and care to all the population by facilitating equitable access, excellent experience, and optimal outcomes (NHSE).

# Digital Inclusion a brief overview

Increasing numbers of people are benefiting from using digital products in their lives with 86% of the population online and using the internet in various ways (Good Things Foundation (a)). The number of people using digital in their everyday lives increased during the first year of COVID-19 (Lloyds bank) with 65% of the population using video calling for the first time and 24% of over 75s increasing their internet use (Good Things Foundation (a)).

However, despite these increases there are still significant parts of the population that are not able to benefit from digital or are struggling to do so. It is estimated that 10 million adults in the UK are at risk of digital exclusion (Lloyds bank) 1 in 5 adults do not have the digital skills needed for everyday life; over 1 in 20 households do not have Wi-Fi- either fixed line or mobile, and; over 2 million households struggled with the cost of internet in 2021 (Good Things Foundation (a)) a situation that may increase with the current cost of living crisis.

Individuals who are digitally included are more connected, can access information and services and save money online. Those who are digitally excluded are less well connected, they have less access to information, they are more at risk of financial exclusion and are unable to benefit from the opportunities digital offers an individual-widening social inequality (Good Things Foundation (a)) and widening the determinants of health (gov.uk).

# Not having access to the digital world means not having access to fundamentals of life. As a result, digital exclusion can exacerbate existing inequalities in society or introduce new inequalities. (Digital Poverty Alliance)

Digital exclusion is not a transitory problem that will resolve with increased exposure and use of digital technology across our everyday lives. It is predicted that 4.5m people (8% of the population) will remain digitally disengaged in 2030 (Lloyds bank). Unless all the underlying (and often hidden) causes of digital exclusion and un-engagement are surfaced, recognised, and addressed, the digital divide will continue to increase.

# Digitally excluded populations and correlations with health inequalities

There are associations between digital exclusion and people living in poverty, people living with a disability, people who are unemployed, and people who have low educational attainment (Ofcom). Older people (65+) are more likely to be digitally excluded (and 42% of people over the age of 75 are digitally excluded) (Good Things Foundation (b)), as are people in lower income groups, people living in insecure or social housing, people living in rural areas, and people whose first language is not English (NHS Digital). People who lack confidence in their literacy (general reading and writing), and/or have low literacy are 4x more likely to be non-users of the internet (Good Things Foundation (c)). A further 29% of the population are considered 'limited' or 'narrow' users of digital (Ofcom). 'Limited' or 'narrow' users are people who only use digital in limited ways, such as for social media or to send an email. They are 8x more likely to be over the age of 65, 4x more likely to be

from lower income households, 1.5x more likely to be from Minority Ethnic groups, 2.7x more likely to have low confidence in their general literacy, 2.3x more likely to have lower educational attainment, and 1.7x more likely to be classed in NRS social grade D&E (Good Things Foundation (b)) and (Good Things Foundation (c)). Nearly 30% of all "never/non users" are women aged 75 or over (age UK) and women are also more likely to only use smart phones and to be limited/restricted users of digital as a result (Ofcom).

Young adults are also more likely to be limited users because they tend to depend entirely on smartphones, have lower incomes, and use digital in limited ways (Ofcom) 42% of young adults do not have broadband or a desktop computer; and 30% (2.1 million) of young people aged 8-25 are at risk of becoming "digital castaways"- at risk of long term digital un-engagement due not having the access needed to meet their needs such as for education (Nominet). Table 1 summarises the populations most likely to be digitally excluded.

#### Table 1 Summary of people most likely to be digitally excluded

Summary of people most likely to be digitally excluded
Older adults >65 and are much more likely to excluded if >75 and more so >85
People who left school at or before 16
People living with a disability
People living in poverty- low income, unemployed
People in insecure or social housing or homeless
People in NRS social grade D&E
People living in rural areas
People with low or lacking in confidence of their literacy
People whose first language is not English
Limited/narrow/restricted users which in addition to digitally excluded users include:
Minority ethnic groups, young adults, women

There are correlations between the populations more likely to be digitally excluded and those more at risk of health inequalities: people who are older, disabled, in worse health, poorer, in less stable housing, and less well educated are most likely to be digitally excluded (Digit). However, there are significant data gaps in relation to health and care populations that may be particularly at risk of digital exclusion including people with protected characteristics, and those more vulnerable to health inequalities such as mental

health, meaning the populations most likely to be affected in the health and care setting are still not fully understood. In addition, in the context of a person's life course, including ill health, an individual's ability to digitally engage is not a static state.

In the absence of reliable data that enables the identification of people at risk of digital exclusion or data that identifies people who are, or are not accessing digital health and care, a key premise of this framework is that everyone is at risk of digital exclusion, including health and care workforce and informal carers. As a result, all digital health and care services, pathways and technologies must be designed to be as inclusive as possible by considering the diverse and complex factors that can lead to individuals being temporarily or permanently excluded from digital health and care.

# A Digital Inclusion Framework for Health and Care

Enablers to digital inclusion are widely recognised as a combination of access, skills, motivation, trust, and accessibility and useability <u>(NHS Digital)</u>, and barriers include lack of awareness; lack of workforce capacity and capability, and poor design <u>(gov.uk)</u>. This framework has been designed specifically for health and care and builds on these recognised enablers and barriers to consider digital inclusion in the health and care setting.

# The development of the Digital Inclusion Framework for Health and care

The framework initially emerged from a firm foundation of years of research by the University of Sussex involving service users, carers and professionals that recognised the need for an interdisciplinary evidence base to understand the diverse and complex nature of digital inclusion and exclusion. As digital health and care has rapidly expanded, in particular since COVID 19, the need to understand and mitigate against digital exclusion and associated health inequalities across all health and care settings became a priority for NHS Sussex, presenting an opportunity to work together with the University of Sussex to develop a digital inclusion framework for health and care.

A diverse set of evidence was used to inform the development of the framework and the practical implications and recommendations for health and care settings. The first version of the framework was developed by conducting an integrative review of barriers and enablers to digital inclusion. This review captured a variety of sources (see references)

including published and forthcoming academic research on different aspects of digital inclusion, national reports providing an overview of the state of digital exclusion (e.g. UK Digital Poverty Evidence Review, UK Consumer Digital Index) and local and national evaluations of digital health and care and digital inclusion-related pilots and programs (e.g. BP@Home and O2sats@home evaluations (NHS Sussex), Remote consultations and digital exclusion evaluations (Brighton and Hove Healthwatch), Connecting Lewes (University of Sussex)).

Thematic analysis of different perspectives and insights into the barriers and enablers to digital inclusion enabled the development a working version of the framework. This version was then tested, further developed, and validated with NHS Sussex collaborators: clinicians, support workers, digital teams, commissioners, voluntary and community sector organisations, library services, local authority colleagues, and public representatives through digital transformation development and engagement activities, community of practice events, and workshops. Interviews with various health and care, digital inclusion, and accessibility related organisations (e.g., ageing 2.0, ability.net) were also conducted with experts on topics such as cognitive accessibility.

The applicability of this framework was also 'sense tested' with collaborators, experts working in this field, and representatives from various Sussex based digital transformation programmes in health and care including from a Primary Care Network (with a ward in the 10% most deprived Lower Super Output Areas when ranked by the Index of Multiple Deprivation (IMD) in England), Musculoskeletal services and the Virtual health programme (for the full list of engagement activities see appendix 1).

As a result, this framework has been developed by an interdisciplinary team of researchers and health and care stakeholders (please see acknowledgments) who have worked towards developing a framework that tackles the problem of digital inclusion in a holistic and human-centred way where digital inclusion is examined from a human perspective across their journey with digital health and care pathways, technologies, and services.

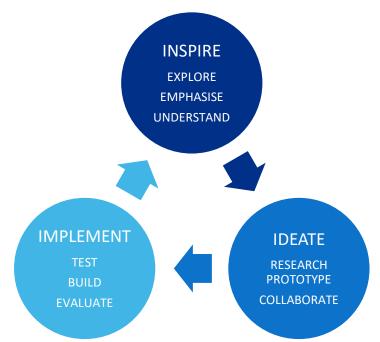


Figure 1 The human-centred process that guided the development of the framework

### Key premises of the framework

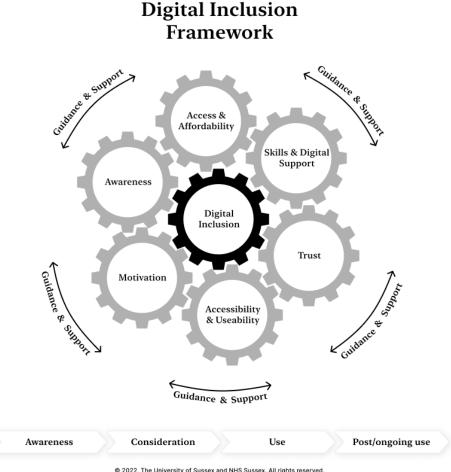
The digital inclusion framework for health and care is unique in that it considers digital inclusion **from the perspective of the service user**, revolving around an individual's journey with digital health and care services, pathways, and technologies: including individual's awareness, consideration, use and post use experience. The digital inclusion framework for health and care maps the enablers of digital inclusion against the course of an individual's journey with digital health and care providing a more longitudinal and holistic view of the problem of digital inclusion and potential solutions in different health and care settings. The framework provides an opportunity to tackle a variety of reasons why people are or could be excluded from digital health and care services – recognising the likelihood and the nature of exclusion will differ in accordance with the stage of their journey. As an example, the impact of, and the actions needed to mitigate against digital exclusion will be different for an individual considering whether to engage versus someone already using the digital service, pathway or technology.

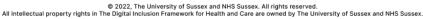
Within the framework enablers to digital inclusions are considered as **awareness**, **access and affordability**, **skills and digital support**, **motivation**, **trust**, **accessibility and useability and guidance and support**. Awareness is an 'anchor' at the start of the journey and an enabler to ongoing engagement on that journey. In addition, in the context of health and care, across all these domains, additional guidance and support (e.g., informational and emotional) could be, and often is, needed to facilitate engagement and prevent people from being unengaged or becoming dis-engaged.

The enablers, presented individually in the sections that follow, are interconnected. As an example, higher digital skills may be associated with higher trust, or higher levels of support may compensate for low skills and confidence, or less accessible and useable technology or pathways. Overall, the framework builds on the circumstances that lead someone to be vulnerable to digital exclusion (not a particular designation such as being older or having lower income).

Figure 2 and Table 2 visualise the framework. Each of the digital inclusion-related theme, captured in the framework contains a health and care service objective and recommendations, accessible by clicking on the 'letter' in the framework (please also see detail in appendix 2).



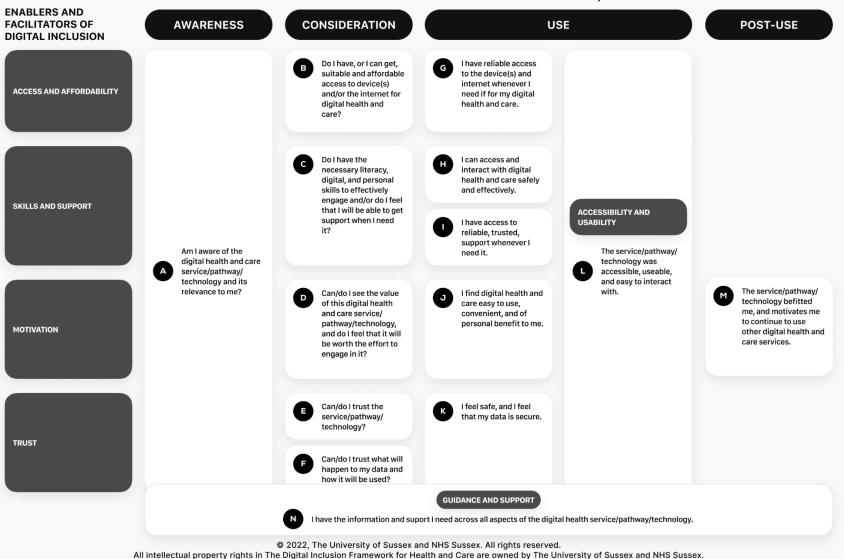




#### Table 2 A Digital Inclusion Framework for Health and Care

#### DIGITAL INCLUSION FRAMEWORK FOR HEALTH AND CARE

A SERVICE USER'S JOURNEY FOR DIGITAL HEALTH SERVICES/TECHNOLOGIES



# Summary of key enablers and barriers to digital inclusion in health and care

The evidence and insights into barriers and enablers to digital inclusion that have been used to develop this framework in the context of health and care are summarised below.

#### Access and Affordability

Access to digital technology(s) that meet individual and service needs and the infrastructure (connectivity) to use them is essential. The type of technology and type of access is also important. Older technology, or intermittent access may not be enough to provide adequate access for health and care technology(s) and pathways due to specification requirements, updates, or the health and care pathway. Affordability is a significant barrier to consistent, reliable access and this includes the cost of the technology itself, the cost of software, licences, wifi/data, and the cost of electricity, especially in the current context of the living crisis. Housing infrastructure, including location, can also be barriers to affordable access.

There are a number of national and local initiatives in place to improve access to technology in the general population including for health. However, whether national and local initiatives will be enough to enable access to the breadth of health and care services, pathways and technologies needs further evaluation.

In the health and care setting the technology(s) and the infrastructure needed to use that technology may have to be provided to ensure people are not disadvantaged by their inability to afford technology that would otherwise benefit them to access equitable health and care.

## Digital Skills and Digital Support

In addition to access, individuals need to have the digital skills and digital support required to use technology as part of a health and care pathway. In the South East of England approximately 18% of the population have either no or low levels of digital skills that make accessing and interacting with any digital technology very challenging (Lloyds Bank). In health and care, more advanced skills are likely to be required and the digital support requirements to enable people to access health and care pathways and technology(s) independently, safely, and effectively can be significant.

Digital support can range from getting someone started, help with updates and troubleshooting, or everyday help to use the product safely and effectively. If the pathway is complex, and/or involves different technology(s) this can increase support needs. The provision of digital support for health and care pathways was a key theme from Sussex engagement, including how to provide this level of support- whether this should be formal or informal and the benefits and risks of both; safety, risk, confidentiality, privacy and safeguarding in the context of health and care; and the capability and capacity of workforce, volunteers and informal carers who may be expected to deliver support, some of whom are likely to need support themselves. Lack of adequate support could increase the risk of user error, reduce trust, and lead to digital un-engagement.

#### **Motivation**

Motivation is primarily associated with an individual's perception that engagement is beneficial to them and adds value to their life. It is required to both engage and then continue to engage in any digital health and care service, pathway and/or technology. An individual's motivation is the most significant enabler to engagement with digital, and it is also the least understood and considered the most difficult barrier to digital inclusion to address (Good Things Foundation (c)). The reasons that people do not engage or choose to disengage with digital are complex, users are heterogeneous, and the context of each digital service and product will be unique (Keeling, University of Sussex).

Common barriers, emerging from engagement, that can be used to inform an understanding of motivation to engage in digital health and care include lack of understanding of the value of digital health and care opportunities for them personally, pathway and product complexity, frustration and being overwhelmed when things are too difficult and there is a lack of support, digital fatigue due to the number of digital products already in circulation, diminished clinician/patient relationships, lack of feedback, and uncertainty about safety and clinical oversight.

The <u>Good Things Foundation</u> identified 4 profiles of non- users in digital and their motivational barriers. These are "It's not for me", "I don't have the right support", "It's too complicated", and "It costs too much". These profiles provide deeper insight into issues such as lack of choice and feeling pressured to use digital, lack of confidence (as an example in an individual's literacy), fear, being overwhelmed, complexity, disproportionate

amounts of effort or support needed to be of personal value, lack of trust and confidence in digital. (See appendix 3).

Researchers at the University of Sussex summarise the causes of un-engagement in digital health and care as incompatibility with the needs of those who will be using the digital product or service; interoperability barriers when technology cannot be integrated with other systems (complexity); inaccessibility, even when technology is low tech because it is not designed for people with low literacy or low skills; and lack of 'human touch' which is particularly challenging for users when the technology is advanced as an example in robotics and artificial intelligence (Keeling, University of Sussex).

Common factors that motivate people to engage with digital health and care (pathway(s) and technology(s)) overlap with other enablers including accessibility and useability. They can be summarised as:

- An understanding of the digital pathways and opportunities that may benefit them
- Individuals being able to see the value of the digital product/service to them and that the effort to engage is worth it.
- Individuals need to believe that they have a 'real' voice and choice.
- It must be easy to use, accessible and require minimal support.
- It needs to be convenient easier and faster access to healthcare services.
- It needs to be cost effective, reducing individual cost including travel time.
- It has got to feel safe and be trusted.
- It needs to feel representative and personal. This will include representing diverse populations and culturally sensitive.

Motivation maintains effort over time and can help overcome digital fatigue. The effort needed to engage is a key barrier and may pose problems in health and care at a time when an individual's resources to engage and learn something new may already be compromised. People with long term conditions that need frequent access to health and care may be more likely to see the benefit of engaging in digital health and care and be willing to put in the effort needed to engage. Conversely someone may not have the motivation to learn something new, as an example, to access their GP about something

they perceive to be a relatively minor issue, which could lead to delays in seeking help and delayed diagnosis.

This presents problems for access to digital health and care because assumptions about future or ongoing engagement cannot be based on an individual's past or current motivation to engage with digital including within health and care settings and will be dependent on an individual's circumstances at any one time, including as that may change over their life course.

## Trust

Trust in the NHS is considered to generally remain high but in the context of digital health and care this may not be the case for all commissioned care including technology providers. Trust in the context of digital inclusion also includes trust in the service, the pathway, the technology, trust in clinical oversight, trust that an individual will be safe, and trust and transparency about how an individual's data is being used. Trust and transparency are needed about what data is going to be collected, how it will be managed, the decisions that will be made using that data, and the motivation behind those decisions (Keeling, University of Sussex). The consequences of a breach of trust are significant, including leading to un-engagement with digital health and care, which can be difficult to recover. The requirement to build and maintain public trust in the use of health and social care data is recognised as essential to the transformation of health and social care (gov.uk).

Digital health and care products recommended, or branded, by the NHS are more likely to be trusted, so it is important that the health and care system is confident any digital technologies they recommend are safe and effective. A 'bank' of trusted technologies that are accessible and useable in the health and care system could be a helpful resource to enable people to access trusted technology independently and more confidently.

Stakeholder engagement has also highlighted that it is not always obvious how people can raise concerns and complain about digital health and care products and pathways, or what governance sits behind these pathways. They highlighted the need to be transparent, to learn from issues, help ensure digital pathways and products are safe and accessible to build and maintain trust.

## Accessibility and Useability

Accessible and useable digital health and care pathways and technology(s) are essential to enable more users to independently, effectively, safely, efficiently, and satisfactorily access and use digital health and care services. Accessibility and useability in digital health and care must consider the entire pathway(s) from the individual user's perspective, not just individual steps, or technology(s). This includes considering the needs of people living with disabilities, permanent or temporary, and how assistive technology(s) interoperate with digital health and care technology(s).

Accessibility is all about removing barriers to access, and useability ensures that technology and pathways can be used safely and satisfactorily, providing the benefits of health and care technology (and pathways) for everyone. Accessible and useable digital health and care pathways and technologies benefit people who do not have disabilities as well as people who do.

The requirement for accessible technology is supported by policy and guidelines (gov.uk), and is subject to digital technology assessment criteria (DTAC) (NHSE). Yet these are not always applied, in part due to several exemptions. The failure to ensure all websites and apps are accessible is highlighted by the <u>Digital Poverty Alliance</u> leading to demands that all websites and digital apps used by essential services must be accessible to everyone who needs to access them, when they need to access them. In the meantime, current accessibility standards do not go far enough to address accessibility (and hence useability) barriers in relation to digital inclusion or consider the use of multiple technology(s) as part of more complex health and care pathways.

For a health and care pathway or technology to be useable the individual needs to be able to use the pathway or technology for its intended purpose and the effort in engaging in that service or technology needs to be proportionate to its intended purpose and perceived value. The individuals experience of a useable health and care service, or technology should be satisfying and inspire future engagement with that service and technology. This is important in health and care where the nature of digital services and technology(s) often require continued usage over multiple time points and in combination with other services and technologies. Useability is not just required for individual instances of use, but across the whole period of use, and pathway. A lack of useability can seriously erode an individual's motivation to engage with a product or service over the long term.

Essential to accessibility and useability in health and care is consideration of the 60% of the population who struggle with health literacy especially when that includes numbers (NHS). Many more people will find processing new and complex information, pathways, or technology difficult especially when unwell, emotionally stressed, or facing other cognitive demands. If information is too complicated this can lead to a sense that digital is 'not for me' and un-engagement, it can also increase the risk of misinterpretation and errors. A basic requirement, therefore, must be the use of plain language presented in accessible ways. This will not only benefit most of the English-speaking population who may struggle with health and care information, it will also help the translation of health and care information, it will also help the translation with higher accessibility needs, and table 4 summarises the main barriers and enablers to digital inclusion in health and care.

#### Table 3 Populations with higher accessibility needs

### Populations with higher accessibility needs

The number of people reporting they had a substantial or long-term disability whether physical or mental increased to 22% of the entire UK population in 2020/21. This includes up to 9% of children, 21% of working age adults and 42% of those at state pension age and many more people will have temporary disability (gov.uk). Disabilities can be categorised as:

- Physical and range from severe immobility to a tremor that affects someone's dexterity
- Sensory which can include vision loss, hearing loss, loss of sensitivity.
- Mental which can include common mental health problems like depression to serious mental illness like psychosis.
- Cognitive such as learning disabilities, mild cognitive impairment and dementia.

In addition: 1 in 6 adults in the UK have very poor literacy skills and 60% of the population struggles with health content that includes numbers and 10% of the UK population have dyslexia which can include dyscalculia (NHS). 20% of children and over 10% of working age adults reporting issues with learning. (gov.uk)

Table 4 Summary of key enablers and barriers to digital inclusion in health and care

	Enablers	Barriers	
ACCESS and	Individuals have access to all the	No access, or limited access to	
AFFORDABILITY	devices and apps that meet their needs.	technology, wifi, data, or electricity.	
	Access to connection, wifi, data, electricity, recognising access	Old / incompatible devices.	
	needs to be consistent for some health and care pathways.	Programmes with frequent updates/high specification requirements.	
		Cost and personal priorities (essential items)	
SKILLS and DIGITAL SUPPORT	Individuals have the skills needed to engage with all necessary technology and	Multiple and/or complicated technologies and pathways.	
	pathways.	Lack of awareness or access to trusted support (formal or	
	Individuals have access to formal or informal (family /friends) support by trusted people	informal). Lack of consistent support at	
	available whenever this is	each stage this could be needed	
	needed.	(e.g., tech, app, update, when there is a problem).	
MOTIVATION	Individuals need to understand and value, and continue to understand and value, the benefit of the technology/pathway to them.	Too complex; too difficult to access, use, understand; too many steps (digital and other), multiple systems; doesn't meet individual need; added cost; not representative or sensitive; effort	
	Must work for the individual- easy to use and convenient, cost effective.	too much for the potential benefit.	
	Outcome is as good as, or better than the alternative.		
TRUST	Individuals have trust in the system, service, pathway and technology.	Lack or loss of trust, which could be due to past experience, lack of human touch, lack of transparency over data, lack of	
	Individuals understand why and how data and technology is being used.	perceived clinical oversight, lack of feedback.	
	Trust in human touch/clinical oversight maintained.	Not recognised or trusted technology/brand.	
	NHS 'brand'		

ACCESSIBILITY and USEABILITY	<ul> <li>The pathway/programme/technology is fully accessible to the whole population it is designed for including people with: <ul> <li>Visual, auditory, and speech and language needs</li> <li>Physical, neurological and cognitive needs <ul> <li>Incl. Dyslexia and neurodiversity</li> </ul> </li> <li>People with low levels of literacy</li> <li>People whose first</li> </ul></li></ul>	Technology and pathways inaccessible to people with physical or sensory needs: technology too difficult/impossible to handle/utilise/access. Technology and pathways inaccessible to people with cognitive, or neurodiverse needs: pathway, information, and information too complicated. Language inaccessible to people with lower literacy levels,
	speech and language	Technology and pathways
	Physical, neurological and	inaccessible to people with
	o Incl. Dyslexia and	needs: pathway, information,
	literacy	
	Individuals find the service/pathway/technology safe	barriers
	and easy to use.	The service/pathway/technology is not easy to use and leads to errors, dissatisfaction, and un- engagement

## Additional considerations

Awareness is a key anchor point in the framework. However there is a general lack of awareness of digital health and care opportunities and individual pathways/technology(s) including by those who would most benefit from them. A communication and information strategy that promotes the benefits and opportunities provided by digital health and care, and how people can be enabled to access these as part of the digital health and care transformation, and in individual health and care pathways would help to raise awareness across the population.

Connected to awareness, and also integral to this framework additional guidance and support is likely to be required in general across the entire service user journey. This

includes raising awareness, information, signposting to technology and other resources that may facilitate engagement with digital health and care, and/or providing direct support including emotional support across the whole user pathway. Informational and emotional support needs to consider all barriers to digital inclusion to enable more of the population to benefit from digital health and care.

The clinical workforce has been identified as in an ideal position to signpost and support individuals to access trusted and appropriate health and care technology(s). Yet the clinical workforce has also highlighted that they do not know all the technologies and pathways that are available, and also do not have the capacity or capability to support individuals to access these. A 'bank' of trusted, accessible, and useable technologies could enable people to have confidence accessing technologies independently.

Workforce is not the focus of this toolkit; however, it is clear from engagement that the clinical workforce has similar needs to the public; digital products and pathways should be designed to be easy to use and accessible for them too. Special attention is needed to lower paid sections of the workforce, including social care carers and volunteers who may be digitally excluded themselves.

There needs to be more focus on the development and implementation of technology and pathways that are accessible and useable and designed for the health and care populations accessing them, rather than the population having to constantly upskill and/or rely on considerable support to engage digitally. In addition to accessible and useable design, suggestions include reducing the frequency of updates, reducing specification requirements, and ensuring compatibility and interoperability across different devices and pathways.

This includes having a single (trusted) access point and having to log on once to digital health and care, familiarity of technology and pathways, including the ability to personalise, be culturally sensitive and representative of individuals accessing services.

# Case Studies for digital inclusion in health and care

To illustrate the challenges faced by some of the population and workforce when navigating digital health and care, and to provide examples of local initiatives designed to

mitigate against digital exclusion and improve access to digital health and care a number of short case studies are available in appendix 4. These include case studies on:

- Health inequalities and addressing digital exclusion in Primary Care
- Tablet loans and building trust to address digital exclusion in Mental Health services
- Digital Ambassadors: Sussex pilot
- Diabetes: sensor- based glucose monitoring systems
- The Connecting Lewes Research Project.
- Accessibility considerations for people who are blind or partially sighted
- Digital Care Homes
- Sheltered accommodation, digital health and care technologies and inclusion for over 55s

# Key messages for Digital Inclusion in Health and Care

- There are significant data gaps including identifying populations at risk of digital exclusion and health inequalities, and the impact of digital exclusion in the context of health and care and clinical outcomes which needs to be addressed.
- Certain populations are more at risk of digital exclusion, which puts them at increased risk of health and care inequalities and possibly health and care exclusion because of digital only/digital first pathways.
- Equitable alternatives to digital health and care services, pathways, and technology must continue to be provided as a choice.
- In the context of health and care and complex technology and pathways everyone should be considered at risk of becoming digitally excluded (at some point along the journey).
- The population is not aware of the opportunities and benefits that (trusted) digital health and care can bring to them as individuals, the health and care system as a whole, or how to access these.
- Access to technology does not automatically mean it is appropriate to access. Old technology or limited access to technology, may not be compatible with higher specification digital health and care technology(s), updates, and more complex pathways.

- Affordability is a significant barrier to digital access and the health and care system may need to find ways to provide technology, connectivity, including electricity, to ensure it is inclusive.
- Advanced digital skills are more likely to be needed in digital health and care due to the range of digital technologies, their complexity, and how they are used within pathways.
- Significant additional guidance, including information, emotional and technological support may be required to enable people to safely and effectively access and interact with digital health and care, avoid user error, and prevent un-engagement due to being overwhelmed.
- If additional (informal) digital support is required, and/or there is a lack of privacy at home, patient confidentiality, privacy, safeguarding, trust, guilt of seeking/needing support, willingness to disclose sensitive information in front of others, and consent, all need to be considered in the context of that individual and each digital health and care pathway/technology.
- The skills and capacity and capabilities of anyone providing digital support must be considered. This includes their willingness and consent to provide this support, their literacy and digital confidence, their own risk of digital exclusion, the quality of their support, the potential for clinical risk, and carer burden.
- Public facing workforce may not have the awareness, capacity, or capability to signpost or support people to access digital health and care opportunities.
- Special attention should be given to sections of the workforce that may themselves be digitally excluded or un-engaged, and informal carers.
- The workforce experiences the same barriers to digital health and care. Ease of use, convenience, and interoperability across systems are motivational enablers for workforce that will support their engagement with digital transformation.
- People are more likely to engage and stay engaged when they see a personal value in doing so, and the effort to learn and engage in something new outweighs the effort required for any alternative.
- Motivational enablers to digital inclusion include ease of use, convenience, cost (and resource) effectiveness.
- Motivational barriers to digital inclusion include complexity, inaccessibility, effort outweighs perceived benefit, lack of trust.

- People value and trust the clinical relationship so lack of human touch, or opaque clinician oversight and feedback could cause people to lose trust and un-engage.
   Feedback to any health and care communication/data input is important.
- Un-engagement of otherwise digitally excluded individuals could happen due to complexity, digital fatigue, lack of feedback, and lack of choice.
- Trust is needed in the service, the pathway, the technology(s), how data is being used and by whom. Transparency and choice are important.
- People need to trust that the digital health and care pathway and technology is as safe as the alternative. There needs to be a mechanism to raise concerns, complaints, and safety issues and access in person support when it is needed by the individual.
- Accessible and useable pathway(s), technology(s) and interoperability is key to enable more independent access, reduce support needs, increase motivation, reduce barriers, and reduce the risk of user error.
- Advanced literacy and numeracy skills, and cognitive accessibility may be needed to safely access and interact with some health and care technologies and pathways.
- All health and care information must be provided in plain language, consider numeracy, risk of errors, and cognitive demand. The use of plain language will also be more translatable.
- It is important to consider the entire patient journey not just individual technologies.
   Complex pathways with otherwise accessible technology(s) can still be a barrier to inclusion and engagement.
- Accessible design benefits everyone and will engage the population and workforce to engage and keep engaged in digital health and care.

# Key Recommendations for Digital Inclusion in Health and Care

The overall aim of this health and care digital inclusion framework is to enable everyone that can benefit from digital health and care to do so, when they need to, and to ensure that inaccessible pathways and technologies are not creating barriers and causing unengagement in digital health and care. Recognising some of these key messages and recommendations will require and integrated and wider system approach, key recommendations that will support the health and care system in achieving this objective include:

- 1. Data sets need to be developed that will enable identification of
  - a. those most at risk of digital exclusion
  - b. those not engaging in digital health and care
  - c. health inequalities associated with digital health and care
  - d. patient insights and experience
  - e. clinical outcomes of digital health and care.
- 2. Special consideration must be given to the populations most likely to be excluded and their specific support needs while recognising that everyone is at risk of being, or becoming digitally excluded, and can quickly become unengaged if digital pathways do not work for them, and/or as their circumstances change.
- 3. A digital inclusion strategy and governance structure should be introduced to mitigate against digital exclusion and help reduce digital health inequalities.
- 4. Establish a communication strategy to raise awareness, benefits, and opportunities of digital health and care to relevant populations in advance of their need to interact with digital health and care.
- 5. All digital health and care services, pathways and technology(s) must be designed to facilitate digital inclusion and equitable access to health and care for the whole population. Access and affordability, skills and digital support, motivation, trust, accessibility and useability, and access to appropriate information and support are key enablers for digital health and care.
- 6. All digital health and care pathway(s) and technology(s) should be designed from the service user's perspective to facilitate digital inclusion at each stage of their journey with digital health and care (their awareness, their consideration, their use, and post use experience).
- Ensure all health and care information, including in digital technology, is accessible and understandable to people with lower literacy/low confidence in their literacy, and limits the cognitive demand needed to engage.
- Health and care technology needs to be designed to be accessible and useable, in isolation and in combination with other health and care technology and assistive technologies. Accessible and useable services, pathways, and technologies will be

user-friendly, safer, increase independence and reduce additional workforce support requirements.

- 9. A 'bank' of trusted technologies that are designed to be accessible, useable, safe, effective and interoperable, in the health and care system would be a helpful resource to facilitate people to more confidently access trusted technology independently.
- 10. Consider the needs of workforce in all digital health and care- including their access, skills, motivation, trust, and the accessibility and useability of the technology they are using to support their work and the service users they support.
- 11. Work with the AHSN and industry partners to develop an industry digital inclusion framework for health and care to enable industry partners design more inclusive and accessible digital health and care solutions.
- 12. Continue to develop and evaluate this digital inclusion framework and design/assessment tool across different health and care pathways and consider the health and social economics of providing technology for relevant populations.

# Applying the Digital Inclusion Framework for Health and Care: assessment/design tool and evaluation

To support the application of this digital inclusion framework for health and care and the design of services, pathways and integrated technologies that are inclusive, accessible and useable, a design /assessment tool accompanies the framework and is available in appendix 5, with an accessibility and useability resource guide in appendix 6.

The framework and design/assessment tool could be used to support equality and quality impact assessments as new digital services and pathways are designed, and could also be beneficial to review existing pathways and services, considering the barriers and enablers to digital inclusion and how to mitigate against these.

This framework and the design/assessment tool have been developed using an agile and evidence-based process. As a result, they will require ongoing testing in different health and care settings and populations to continue to validate and test relevance, to ensure useability by the health and care system, and to measure their impact.

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# References

Ahmed, W., Vidal-Alaball, J., Downing, J., & López Seguí, F. (2020). COVID-19 and the 5G Conspiracy Theory: Social Network Analysis of Twitter Data. Journal of Medical Internet Research, 22(5), e19458. https://doi.org/10.2196/19458

Alzheimer's Society. (2022). *Tips for dementia-friendly documents*. Retrieved May 5, 2022, from https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/tips-dementia-friendly-documents

Blank, G., Dutton, W. H., & Lefkowitz, J. (2019). Perceived Threats to Privacy Online: The Inter-net in Britain, the Oxford Internet Survey, 2019 http://dx.doi.org/10.2139/ssrn.3522106

Centre For Ageing Better. (2021). Age UK – COVID-19 and the digital divide. Centre for Ageing Better. https://ageing-better.org.uk/stories/age-uk-covid-and-the-digital-divide

CHL Foundation. (2022). *Conseils Bien-être*. Retrieved July 1, 2022, from http://www.chlfoundation.org.uk/

Department for Digital, Culture, Media & Sport. (2017). Digital Inclusion Evaluation Toolkit. GOV.UK. Retrieved April 6, 2022, from https://www.gov.uk/government/publications/digital-inclusion-evaluation-toolkit

Department for Digital, Culture, Media & Sport. (2017). *UK Digital Strategy*. GOV.UK. Retrieved June 11, 2022, from https://www.gov.uk/government/publications/uk-digital-strategy

Digital Poverty Alliance. (2022). UK Digital Poverty Evidence Review 2022. https://digitalpovertyalliance.org/uk-digital-poverty-evidence-review-2022/

French, T., Quinn L., and Yates S. (2019). Digital Motivation: Exploring the reasons people are offline. Good things Foundation. https://www.goodthingsfoundation.org/insights/digital-motivation/

Good Things Foundation. (2021). *Building a Digital Nation*. Retrieved July 11, 2022, from https://www.goodthingsfoundation.org/insights/building-a-digital-nation/

Good Things Foundation (2021). *The digital divide*. Retrieved June 10, 2022, from https://www.goodthingsfoundation.org/the-digital-divide/

Good Things Foundation (2022). *Motivational barriers of non-users of the internet*. Retrieved June 20, 2022, from https://www.goodthingsfoundation.org/insights/digitalmotivation/

GOV.UK. (2018). The future of healthcare: our vision for digital, data and technology in health and care. Retrieved August 15, 2022, from

https://www.gov.uk/government/publications/the-future-of-healthcare-our-vision-for-digitaldata-and-technology-in-health-and-care/the-future-of-healthcare-our-vision-for-digital-dataand-technology-in-health-and-care GOV.UK. (2019). *Health matters: reducing health inequalities in mental illness*. Retrieved April 24, 2022, from https://www.gov.uk/government/publications/health-matters-reducing-health-inequalities-in-mental-illness/health-matters-reducing-health-inequalities-in-mental-illness

GOV.UK. (2022). *Data saves lives: reshaping health and social care with data*. Retrieved June 20, 2022, from https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-saves-lives-reshaping-health-and-saves-lives-reshaping-health-and-saves-lives-reshaping-health-and-saves-lives-reshaping-health-and-saves-lives-reshaping-health-and-saves-lives-reshaping-health-and-saves-lives-reshaping-health-and-save

GOV.UK (2022). *Family Resources Survey: financial year 2020 to 2021*. Retrieved May 6, 2022, from https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021

GOV.UK. (2022). Understanding accessibility requirements for public sector bodies. Retrieved August 23, 2022, from https://www.gov.uk/guidance/accessibility-requirements-for-public-sector-websites-and-apps

Green, M., and Rossall, P. (2013). *Digital inclusion evidence review*. Retrieved May 5, 2022, from https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/activecommunities/rb\_sept13\_age\_uk\_digital\_inclusion\_evidence\_review.pdf

Hadjis van Thiel, J. (forthcoming). An exploration of local government approach to multiple regulatory and political uncertainties. Unpublished doctoral dissertation submitted to a degree at Science Policy Research Unit, University of Sussex, United Kingdom.

Healthwatch Brightonandhove. (2020). Accessing health and care services – findings during the Coronavirus pandemic: Executive summary and Full report. Retrieved May 12, 2022, from https://www.healthwatchbrightonandhove.co.uk/report/2020-10-14/accessing-health-and-care-services-%E2%80%93-findings-during-coronavirus-pandemic+

Healthwatch Brightonandhove. (2021). *Digital Exclusion – Briefing report*. Retrieved June 20, 2022, from https://www.healthwatchbrightonandhove.co.uk/report/2021-01-29/digital-exclusion-%E2%80%93-briefing-report

Healthwatch England. (2022). The public's experience of monitoring their blood pressure at home. Retrieved June 14, 2022, from https://www.healthwatch.co.uk/report/2022-04-26/publics-experience-monitoring-their-blood-pressure-home

The Health Foundation. (1970). Quantifying health inequalities in England. Retrieved June 14, 2022, from https://www.health.org.uk/news-and-comment/charts-and-infographics/quantifying-health-inequalities

The Health Literacy Place. *Use simple language*. (n.d.). Retrieved June 29, 2022, from https://www.healthliteracyplace.org.uk/toolkit/techniques/use-simple-language/

Hernandez, K., Faith, B. (2022). Measuring digital exclusion: Why what is counted is also what counts . Digit. Retrieved June 27, 2022, from https://digit-research.org/data\_commentaries/measuring-digital-exclusion/

Hiteva, R. 2019, Report on Digital Champions and inclusion in social housing, Orbit sponsored project (2018-2019), University of Sussex, United Kingdom.

Hiteva, R., O'Donovan, C. and Simpson, K. (forthcoming) Environmental impact of digital technologies for health and wellbeing in the home, EPSRC project (2021 -2023), University of Sussex, United Kingdom.

Hiteva, R. & Hadjis van Thiel, J. (forthcoming). Connecting Lewes. University of Sussex, Science Policy Research Unit, United Kingdom.

Ibrahim, I., & Abdulazeez, A. (2021). The role of machine learning algorithms for diagnosing diseases. Journal of Applied Science and Technology Trends, 2(01), 10-19.

Keeling, D.I., de Ruyter, K., Mousavi, S. and Laing, A. (2019). Technology push without a patient pull: Examining digital unengagement (DU) with online health services. European Journal of Marketing, Vol. 53, No 9., pp. 1701-1732.

Lloyds Bank. (2021). Essential Digital Skills. Third Edition—Benchmarking the Essential Digital Skills of the UK. Retrieved June 10, 2022, from https://www.lloydsbank.com/banking-with-us/whats-happening/consumer-digital-index/essential-digital-skills.html

Lloyds Bank. (2021). *UK Consumer Digital Index 2021*. https://www.lloydsbank.com/banking-with-us/whats-happening/consumer-digital-index.html

Mangin, D., Parascandalo, J., Khudoyarova, O., Agarwal, G., Bismah, V., & Orr, S. (2019). Multimorbidity, eHealth and implications for equity: a cross-sectional survey of patient perspectives on eHealth. BMJ open, 9(2), e023731.

NDTi (n.d.). *Top Tips to help with Digital Inclusion*. Retrieved April 21, 2022, from https://www.ndti.org.uk/resources/publication/top-tips-to-help-with-digital-inclusion

NHS. (2021). *Health information in other languages*. nhs.uk. Retrieved May 10, 2022, from https://www.nhs.uk/about-us/health-information-in-other-languages/

NHS Digital. (2022). *Why digital inclusion matters to health and social care*. Retrieved May 25, 2022, from https://digital.nhs.uk/about-nhs-digital/our-work/digital-inclusion/digital-inclusion-in-health-and-social-care

NHS Digital (n.d). *What we mean by digital inclusion*. Retrieved May 27, 2022, from https://digital.nhs.uk/about-nhs-digital/our-work/digital-inclusion/what-digital-inclusion-is

NHS England. (2021). *Help us to shape Core20PLUS5: NHS England and NHS Improvements approach to tackling health inequalities.* Retrieved May 2, 2022, from https://www.england.nhs.uk/blog/help-us-to-shape-core20plus5-nhs-england-and-nhs-improvements-approach-to-tackling-health-inequalities/

NHS England (2022). Supporting information for ICS leads Enablers for success: virtual wards including hospital at home. England.Nhs.Uk. Retrieved May 5, 2022, from https://B1382\_supporting-information-for-integrated-care-system-leads\_enablers-for-success\_virtual-wards-including-hos.pdf

NHS England Transformation Directorate. (n.d.). *Digital Technology Assessment Criteria* (*DTAC*). Retrieved May 17, 2022, from https://transform.england.nhs.uk/key-tools-and-info/digital-technology-assessment-criteria-dtac/

NHS in Greater Manchester (2015). *Delivering Effective Services for Children and Young People with ADHD*. ADHD Project Subgroup CAMHS Advisory Group. Retrieved July 2, 2022, from https://www.england.nhs.uk/north-west/wp-content/uploads/sites/48/2019/03/GM-wide-ADHD-guidance.pdf

NHS Race and Health Observatory. (2022). *Ethnic Inequalities in Healthcare: A Rapid Evidence Review*. Nominet. (2021). Digital Youth Index 2021. https://www.nominet.uk/wp-content/up-loads/2021/12/Nominet-Digital-Youth-Index-Report-2021.pdf

NHS.UK (2021). *Health literacy - NHS digital service manual*. Retrieved June 20, 2022, from https://service-manual.nhs.uk/content/health-literacy

Nominet.UK. (2021). *Digital Youth Index 2021*. https://www.nominet.uk/. Retrieved May 10, 2022, from https://www.nominet.uk/wp-content/uploads/2021/12/Nominet-Digital-Youth-Index-Report-2021.pdf

Ofcom. (2012). Adults' Media Use and Attitudes report 2022. https://www.ofcom.org. uk/\_\_\_data/assets/pdf\_file/0020/234362/adults-media-use-and-attitudes-report-2022.pdf

Ofcom. (2022). *Digital divide narrowed by pandemic, but around 1.5m homes remain offline*. Retrieved April 19, 2022, from https://www.ofcom.org.uk/about-ofcom/latest/media/media-releases/2021/digital-divide-narrowed-but-around-1.5m-homes-offline

ONS (2020). 'Frequency of internet use, population counts, by age group, Great Britain, 2019'. Available online at: https://www.ons.gov.uk/peoplepopulationandcommunity/ householdcharacteristics/homeinternetandsocialmediausage/adhocs/11389frequencyofint ernetuse populationcountsbyagegroupgreatbritain2019

The Plain English Campaign. (2022). *How to write medical information in plain English.* Retrieved June 6, 2022, from http://www.plainenglish.co.uk/medical-information.html

Pun, K. (2016). *Dos and don'ts on designing for accessibility*. Accessibility in Government. Retrieved June 2, 2022, from https://accessibility.blog.gov.uk/2016/09/02/dos-and-donts-on-designing-for-accessibility/

Sounderajah, V., Clarke, J., Yalamanchili, S. et al. (2021). A national survey assessing public readiness for digital health strategies against COVID-19 within the United Kingdom. Sci Rep 11, 5958. https://doi.org/10.1038/s41598-021-85514-w

Suetterlin, K. (2021). *UX Writing for Everyone: What Neurodiversity can Teach us*. UX Magazine. Retrieved April 7, 2022, from https://uxmag.com/articles/ux-writing-for-everyone-what-neurodiversity-can-teach-us

Sussex Health and Care Partnership. (2022). *Health and care in Sussex - Deliberative engagement findings.* Sussex Health and Care Partnership. Retrieved April 1, 2022, from https://www.sussex.ics.nhs.uk/

Sussex Health and Care Partnership (2022). Sussex Covid Oximetry @ Home service – Service Evaluation. https://www.sussex.ics.nhs.uk/nhs-sussex/key-documents/

Tian, K. (2022). *Designing Out Digital Unengagement with Co-Creation A literature Review* [Literature Review]. Kent, Surrey and Sussex Academic Health and Science Network.

Walker, M. (2022). *Useful Accessibility Resources and Links*. AbilityNet. Retrieved April 20, 2022, from https://abilitynet.org.uk/accessibility-services/useful-resources

Wills, L. (2021). Cognitive Accessibility for digital health. Academia.Edu. https://www.academia.edu/48949314/Cognitive\_Accessibility\_for\_digital\_health

Wills, L., & Bailey, T. (2022). *Cognitive Accessibility for Digital Health: 2020-2021*. Retrieved June 27, 2022, from https://www.academia.edu/79399423/Cognitive\_Accessibility\_for\_Digital\_Health\_2020\_20 21+

Zeidan, J. et al. (2022) *Global prevalence of autism: A systematic review update*. Autism Res. (5):778-790. doi: 10.1002/aur.2696. Epub 2022 Mar 3. PMID: 35238171; PMCID: PMC9310578.

# Appendices Appendix 1: Engagement for framework development

1 <sup>st</sup> Stakeholder workshop	March	Clinicians, commissioners, digital, virtual health, and population health teams	
User reference group digital first	May	Public, community, and voluntary sector representatives	
User reference group virtual health	June	Public, community, and voluntary sector representatives	
2 <sup>nd</sup> Stakeholder workshop	July	Public representatives, clinicians, commissioners, digital, virtual health, population health teams, VSEC, local authorities	
'test' with Primary care network	July September	GPs, primary care manager, community support staff	
'test' with Musculoskeletal services	August	Clinical leads, commissioners	
'test' with frailty Virtual ward	September	Public representatives, clinicians, commissioners, digital, virtual health, population health teams, VSEC, local authorities	
'test' with Enhanced Health in Care Homes	September	Sussex Local authorities, community and acute Services, commissioners, digital team.	
User reference group digital first	September	Public, community, and voluntary sector representatives	
Other engagement	July-September	Various NHS Sussex, VSCE, health and care, accessibility, and digital inclusion programmes and agencies.	

# Appendix 2: Digital inclusion framework for health and care, objectives, and recommendations

To use this framework, refer to the corresponding letters, statements, user insights, and recommendations in the text below. In the digital version these will link.

		Awareness	Consideration	Use		Post-use
Enablers and Access and Affordab facilitators of digital inclusion Skills and Support		Am I aware of the digital health and care service/pathway/tec hnology and its relevance to me?	to device(s) and/or the internet for digital health and care?	I. I have access to reliable,	Accessibility and Useability L. The service/pathway and technology was accessible.	
	Motivation		D. Can/do I see the value of this digital health and care service/pathway/technology, and do I feel that it will be worth the effort to engage in it?	need it. J. I find digital health and care easy to use, convenient, and of	useable, and easy for me to interact with.	M. This service/pathway/technolo y befitted me, and
		E. Can/do I trust the service/pathway/technology? F. Can/do I trust what will happen to my data and how it ill be used?	K. I feel safe, and I feel that my data is secure.		motivates me to continue to use other digital health and care	

# A

# Am I aware of the digital health and care service/pathway/technology and its relevance to me?

## Health and care service users' perspective:

- What is digital health and care?
- How can digital health and care services, pathways and technology(s) support my individual health and care needs?
- What health and care pathways and technologies would be of personal benefit to me?
- How do I access trusted health and care pathways and technologies?

# Health and Care Digital Inclusion objective:

# Our population is aware of digital health and care services/pathways and technologies and their relevance to them as individuals.

# **Recommendations:**

- Develop a digital health and care communication strategy (national, regional, local, population level).
- Use all health and care opportunities to raise awareness of trusted digital health and care transformation and individual pathways/technologies to relevant populations.
- Consider workforce requirements (including their capacity and capability) to raise awareness and support/signpost people to relevant/trusted digital health and care.
- Develop a library of trusted, accessible, useable, digital health and care

services/pathways/technologies to aid people accessing these independently

- Collaborate with other agencies working to improve digital access and skills to also promote digital health and care including:
  - Community/voluntary sector groups
  - o Libraries
  - o Local authorities

# Pay special attention to:

For each service/pathway/technology pay special attention to groups most likely to benefit from digital health and care, e.g., people on polypharmacy are more likely to benefit from NHS app for repeat prescriptions, specific Long-Term Conditions (LTC) and populations most affected by those.

# В

# Do I have, or I can get, suitable (and affordable) access to device(s) and/or the internet for digital health and care?

# Health and care service users' considerations:

- Do I have suitable access to device(s) so that I can access and interact with digital health and care whenever I need to?
  - Will my current device work with this health and care technology?
- If I don't have reliable access, do I know where I can get access to the device(s) needed?
- Do I have the wifi/data/electricity services that I need to access and interact with digital health and care whenever I need to?
- Can I afford to buy and maintain a suitable device, and the wifi, data, electricity services needed to access and interact with digital health and care whenever I need to?
- If I can't afford the device, the wifi, data, or electricity services, are there alternative (reliable) ways to access this which would enable digital health and care to be accessible to me?

# Health and care system digital inclusion objective:

Our population has suitable access or can get suitable access to devices and/or the internet so they have equitable access, and can interact with, and benefit from digital health and care.

# **Recommendations:**

- Understand specification requirements for each digital health and care technologyis this technology fully useable on all devices our population has access to, and if not how will gaps be filled?
- Ensure service users are not excluded, or disadvantaged, from accessing equitable health and care because they cannot afford the appropriate technology, wifi, data, and electricity they need.
- Ensure service users <u>understand</u> that they will not be excluded from the benefits of health and care if they do not have access to appropriate devices or cannot afford to run them Through provision of devices etc. or equitable health and care

alternative.

- Provide technology and connection for the highest health and care need populations to enable them to access and interact with digital health and care.
  - Mechanisms to do this could include through direct provision or loan of relevant equipment, or 'prescribing' appropriate technology etc.
  - Remove data charges for an individual's essential health-related services (e.g., NHS app)
- Collaborate with other agencies working in this area to provide access to technology and data including:
  - Community/voluntary sector groups
  - o Libraries
  - Local authorities
  - Partnership with internet service providers

# Pay special attention to:

People on low/no income People in insecure/social housing/homeless Older adults 'Limited' users: Ethnic Minorities, women, younger adults

# С

# Do I have the necessary literacy, digital, and personal skills to effectively engage and/or do I feel that I will be able to get support when I need it?

# Health and care service users' considerations:

- Is this service/pathway/technology information accessible to me, written in a language and format that I can understand? Can the information be translated?
- Do I feel the internet and/or this digital health and care service/pathway/technology will be easy for me to access and interact with?
- Do I have the (literacy, digital, and personal) skills needed to interact with this service/pathway/technology safely and effectively?
- Do I have the ability/confidence/motivation/energy to upskill if needed? What support is available to help me with this?
- Could I benefit from this pathway/service/technology if the right support was available?
- Can I easily and confidently access the support that I may need (friends, family, community, or formal support)?
  - Am I willing to ask and share data to do this?
- Will any support that can be provided be enough for me to then feel I can safely and effectively access and interact in digital health and care service/pathway/technology?
- Will this technology interoperate with other (health/care/assistive) technology I need to use?

# Health and care system digital inclusion objective:

Our population will be enabled to access and interact with digital health and care safely and effectively regardless of their literacy, digital or personal skills

### **Recommendations:**

- Ensure the service/pathway/technology is designed to be as easy to access and interact with as possible for all health and care service users.
  - Reduce the literacy, digital, and personal skills that will be necessary to access and interact in this digital health and care service/pathway/technology.
  - Ensure all the service/pathway/technology information that is public facing is accessible, written in plain language, and is translatable.
  - Ensure the digital health and care pathway/technology is interoperable with assistive technologies and other health and care pathways/digital products.
  - Move towards single sign-on (SSO) where users are asked to enter their login credentials one time to access all health and care related applications.
- Provide additional skills training where there are known skills requirements.
- Provide service/pathway/technology support whenever that is needed to ensure safe and equitable access.
- Collaborate with other agencies working in this area to develop digital skills and confidence in using technology including:
  - Community/voluntary sector groups
  - o Libraries
  - Local authorities
  - Private sector/NGOs

### Pay special attention to:

People with low literacy/low confidence in their literacy People who left school at/before 16 People in NRS social grades D&E People whose first language is not English People living with disabilities Older adults

D

### Can/do I see the value of this digital health and care service, pathway, technology, and do I feel that it will be worth the effort to engage in it?

### Health and care service users' considerations

- How will I personally benefit from this digital health and care service/pathway/technology?
- How will it be easier and more convenient or me?
- Will it be worth the effort that I'll need to put in to access and interact with it?
- Are other people, like me, already benefitting from this digital health and care service/pathway/technology?

## Health and care system digital inclusion objective:

# Our population can see the value of accessing and interacting with relevant digital health and care services/pathways/technologies.

### **Recommendations:**

- Ensure the benefits of using digital health and care are explicitly clear, in written and other formats including how it has benefited other similar/representative populations.
- Pay special attention to populations where more personalised/health specific information may be needed.
- Design easy to use, convenient services/pathways/technology that require minimal individual effort in order to engage.

### Pay special attention to:

- People with lower literacy/confidence in their literacy
- People who left school at/before 16
- People in NRS social grades D&E
- People whose first language is not English
- Older adults

### Е

### Can/do I trust the digital service/pathway/technology?

### Health and care service users' considerations:

- Do I trust the NHS/care system?
- Do I trust digital?
  - Can I be scammed? Can my device get a virus? Can my identity be taken?
- Do I trust this digital health and care service/pathway/technology?
  - Do I trust information provided over a digital service? How do I know this information is reliable?
  - Will it be as safe or safer to use than the alternative?
  - o Do I trust there will be enough clinical oversight for my condition?
  - Will I still be able to see someone face to face if I need to?
  - Will I feel safe using this service?
  - Is there any negative press or any rumours in my community about this service/pathway/technology?
- Do I trust my abilities to interact with this digital health and care?
  - Do I trust my own skills and ability to access and interact with this service/pathway/technology?
  - o Does the NHS/service trust me with my health and care information?
- What happens if something goes wrong?

### Health and care system digital inclusion objective:

### Our population can, and does, trust in this service/pathway/technology

### **Recommendations:**

- Pay special attention to populations more likely to mistrust health and care services (e.g., mental health, asylum seekers)
- Build and maintain trust in digital health and care by only using tested/trusted/reliable/secure technology.

- Ensure clinical safety and clinical oversight is transparent and built into the pathway.
- Ensure service users can easily feedback any issues, concerns, adverse events, complaints.

### Pay special attention to:

Everyone - but additional focus may be needed for populations less likely to trust health and care, e.g., people accessing mental health services or asylum seekers.

### F Can/do I trust what will happen to my data and how it will be used?

### Health and care service users' perspective:

- Can/do I trust the health and care system with my personal data and how it is being used?
- Can/do I trust the technology companies I am asked to submit my data too?
- Can I easily find out what will happen to my data, who will have access to this data, how will it be used if I want to?
- Can I choose how my data is used?

### Health and care system digital inclusion objective:

# Our population can, and does trust, what is happening to their data and how it is being used

### **Recommendations:**

- Be transparent about happens to data, data security, and how health and care data can be used to benefit the individual.
- Avoid transferring data through third parties.
- Use NHS brand to build trust in service/pathway/technology.
- Be aware of overwhelming people with information- some people will trust the NHS and will be burdened by too much information. Others will want access to the details.

### G

## Do I have reliable access to the device(s) and the internet whenever I need it for my digital health and care?

### Health and care service users' experience:

- I can access and interact with the digital health and care technology on my own device, or a device I have access to whenever I need to.
- If I'm borrowing/sharing access that is proving reliable and confidential enough to meet my health and care needs currently.
- The digital health and care technology works well with my device.
- Whether I need constant or intermittent connection to wifi/data for digital health and care I can access this when I need it for my health and care needs
- I can either afford to use the internet or buy data to support this digital health and

care service/technology or has this been provided for me.

- This technology interoperates with other (health/care/assistive) technology I need to use.

### Health and care system digital inclusion objective:

All our service users have reliable access to devices and the internet when they need it to enable them to access and interact with digital health and care

**Recommendations:** 

See B

### Pay special attention to:

See B

Н

### Can I access and interact with digital health and care safely and effectively?

### Health and care service users experience:

- I find using the Internet/this health and care pathway/ technology easy and convenient to use because it meets my literacy, digital and personal needs.
- When needed, I have access to reliable support to enable me to access and use this health and care pathway/technology.
- This service/pathway/technology interoperates with the other (health/care/assistive) technology I need to use.
- I can understand and interact with the digital health and care pathway/technology because the information is provided in plain language and is translatable.

### Health and care system digital inclusion objective:

# All our service users can access and interact with digital health and care safely and effectively

### **Recommendations:**

- Ensure digital health and care pathways and technologies are easy and convenient to use (accessible and useable)
- Design digital health and care pathways to require the least amount of additional digital support necessary.
- Build in provision of support at the least inconvenience to the individual/population concerned
- Ensure all information is accessible, written in plain language and is translatable.
- Ensure the pathway/technology interoperates with assistive technologies/other digital health and care pathways/technologies.
- Ensure there is a system in place to monitor complaints, safety data, outcomes.

### Pay special attention to:

People with low literacy/low confidence in their literacy People who left school at/before 16 People in NRS social grades D&E People whose first language is not English People living with disabilities Older adults

#### 

### Do I have access to reliable, trusted, support whenever I need it?

#### Health and care service users' experience

- I can access digital, service, pathway, and technology support whenever I need it.

- I find that support helpful.

- If I am providing support to a friend/family member to access digital health and care I know where I can access support.

#### Health and care system digital inclusion objective:

### All our service users have access to reliable, trusted, support whenever they need it

#### **Recommendations:**

- Design digital health and care services/pathways/technologies to be accessible and useable to reduce the amount of additional support needed.
- Design support requirements into the service/pathway/technology (digital prompts/personal support).
- Understand formal support requirements and who will deliver that including workforce capacity and capabilities.
- Avoid the need for informal support in more complex or sensitive health and care pathways.
- If informal support is needed consider the support needs of informal carers/workforce, their skills, capacity and capability, and the service user's right to confidentiality and privacy.

### Pay special attention to:

People with low literacy/low confidence in their literacy People who left school at/before 16 People in NRS social grades D&E People whose first language is not English People living with disabilities Older adults

#### J

#### Do I find it easy to use, convenient, and of personal benefit to me?

#### Health and care service user's experience:

This digital health and care service/pathway/technology is an easy, safe, and convenient way to access and receive health and care.

I understand what is happening, what I need to do, and how to do it.

### Health and care system digital inclusion objective:

### Our service users value digital health and care and will continue to use it.

### **Recommendations:**

- Design easy to use, convenient, accessible services/pathways/technology that require minimal individual effort in order to engage and remain engaged.
- Ensure the digital health and care pathway/technology is interoperable with assistive technologies and other health and care pathways/digital products.
- Ensure the digital health and care pathway is as good as, if not better than the alternative for service users.

### K Do I feel safe, and feel that my data is secure?

### Health and care service users' experience:

- My health and care needs are met, and I feel safe.
- When I have a concern, I know how to raise it, and that it will be responded to.
- I am confident I am receiving the right advice and know what will happen/what I need to do next.
- The health and care service/pathway/technology helps me understand and manage my condition.
- The health and care service/pathway/technology picks up any health and care concerns and facilitates a safe and effective response.
- My personal data is kept safe and is only used by trusted health and care providers.

### Health and care system digital inclusion objective:

# All our service users feel safe and know that their data is safe when using digital health and care

### **Recommendations:**

- Build and maintain trust in digital health and care by only using tested/trusted/reliable/secure technology that is clinically effective.
- Ensure information is presented in accessible ways.
- Ensure clinical safety and clinical oversight is transparent and built into the pathway.
- Feedback to service users when they enter data, so they know this has been reviewed and if they need to take action.
- Ensure service users can easily feedback any issues, concerns, adverse events, complaints.

### L

## The service/pathway and technology was accessible, useable, and easy for me to interact with

\*Accessibility = are ALL users able to access an equivalent user experience, however they

### encounter product or service

\*Useability = how well a specific user in a specific context can use a product/design to achieve a defined goal effectively, efficiently, and satisfactorily.

### Health and care service user perspective

- I understand how to use this digital health and care service/pathway/technology
- I can easily access and use this digital health and care service/pathway/technology
- I can safely and effectively interact with it
- If I need assistive technology, or other health and care pathways/digital products it interoperates easily with this digital health care pathway/technology.

### Health and care system digital inclusion objective:

# All of our service users find digital health and care services/pathways/technologies accessible and useable

### **Recommendations:**

- Design the digital service/pathway/technology to be accessible and easy to use for all service users and workforce.
  - Design the digital health and care service/pathway/technology with literacy and cognitive accessibility requirements as core standard.
  - Ensure the digital health and care pathway/technology is interoperable with assistive technologies and other health and care pathways/digital products.
  - Move towards single sign-on (SSO) where users are asked to enter their login credentials one time to access all health and care related applications.
  - Design the digital health and care service/pathway/technology in a way that users can accomplish goals easily and in a familiar way (e.g., the interfaces need to be designed in a way that is familiar to what users are asked to do when using other digital services).

### Pay special attention to:

People living with disabilities People with low literacy/low confidence in their literacy People who are unwell/stressed/neurodiverse (cognitive requirement) People whose first language is not English Older adults

### Μ

# This service/pathway/technology benefitted me, and motivates me to continue to use digital health and care

### Health and care service user's reflection

- This digital service/pathway/technology provided easier and more convenient access to health and care

- This service/pathway/technology was useful and beneficial to me.
- This service/pathway/technology was safe and effective.

I had the information and support I needed when I needed it.

- I was given the opportunity to feedback including any concerns I may have had, and these were responded to.

### Health and care system digital inclusion objective:

# Our population experience that they benefit from digital health and care and are motivated to continue using it

### **Recommendations:**

- Routinely measure:
  - Populations at risk of digital exclusion
  - Populations not accessing digital health and care
  - o Access and usage data of digital technologies
  - Service user experience and satisfaction in relation to the service, pathway, technology
  - Clinical outcomes including safety
- Collate and respond to feedback and any clinical issues raised.

### Ν

# I have the guidance and emotional support I need across all aspects of the digital health service/pathway/technology.

### Health and care service user's requirements

I know where I can get information about digital health and care if I need it

I know where I can get support for digital health and care if I need it

I know where I can raise concerns and feedback about digital health and care.

The information and support that is available is accessible to me.

I get the same (or improved) access to personalised information and support that I would get if I was receiving non digital health and care.

### Health and care system digital inclusion objective:

Our population knows where they can access information and support about digital health and care throughout their journey of awareness, consideration, use and post use of digital health and care

### **Recommendations:**

Ensure people accessing digital health and care have the same (or improved) access to personalised, accessible and useable health and care information and support as if they were accessing non digital health and care.

Information and support must be presented in accessible and useable ways to individuals including taking into account cultural sensitivities.

If not provided in person, prompts and feedback mechanisms must be included to deliver support when it is needed or signpost people to where support can be easily located.

## **TECHNOLOGY PROVIDER RECOMMENDATIONS**

### Clinical safety: (NICE guidelines)

Technology has been tested with target population, including as part of a pathway- as

relevant

## Accessibility and Useability: (DTAC + our recommendations)

Design all health and care technology (and associated information) to be fully accessible and useable including:

- Language designed for people with low literacy/low confidence in their literacy
- Fully translatable
- Reduce cognitive requirements
- Designed for people with disabilities (physical, sensory, cognitive, mental)
- Fully interoperable with other health and care technology and assistive technology

### Technology specification:

Ensure digital health and care technology can be used on various digital devices. Reduce high specification requirement of technology where possible

Reduce data requirements for technology

Consider how critical information/basic functionalities available without the internet connection/with low bandwidth.

Avoid frequent updates.

### Data protection:

Ensure data is safe and used only as it is required to be.

### User experience:

Ensure users get feedback following any interaction, and know what will happen/what they need to do

Enable users to provide technology feedback as standard

Provide easy access to support

## Appendix 3: Good things foundation- motivational barriers to non-use of the internet

Reasons for being	Reasons for being nonusers of the internet Good Things foundation					
Profile	Size of population affected	Characteristics of population most likely to fit this profile	Examples of why this is a barrier			
"It's not for me"	61% of non- users and 7.4% of the whole adult population	People with lower educational attainment, lower literacy, and from NRS social grades D&E.	This could be because people don't see the personal benefit of going online, or they are fearful of doing so which could be related to previous bad experiences, feeling forced to use it, or because it is overwhelming.			
"I don't have the right support"	25% of non- users and 3.1% of the whole adult population	Older adults, and/or people with lower educational attainment and lower confidence in their literacy.	This could be because they don't have the right equipment, or support by trusted people at the times it is needed, and this can be disempowering.			
"It's too complicated"	22% of non- users, and 2.7% of the whole adult population	Older adults, in lower skilled work, from NRS social grades D&E and/or people with lower educational attainment.	This may be due to lack of exposure through work, and lack of confidence but also because the technology and associated programmes are just too complicated and trying to get the level of support needed is not perceived as adding value or worth the effort.			
"It costs too much"	15% of non- users, and 1.8% of the whole adult population	Older, and young adults, people from low-income households, and NRS social grades D&E.	The reasons behind this are income and affordability, as well as being forced to use the internet to claim benefits <i>and incur those costs,</i> and perceived lack of value for money.			

## Appendix 4: Case Studies

These primarily Sussex case studies provide insights into various aspects of digital inclusion in relation to health and social care and have fed into the development of this framework. They include:

- 1. Health inequalities and addressing digital exclusion in Primary Care
- 2. Tablet loans and building trust to address digital exclusion in Mental Health services
- 3. Digital Ambassadors: Sussex pilot
- 4. Diabetes: sensor- based glucose monitoring systems
- 5. The Connecting Lewes Research Project.
- 6. Accessibility considerations for people who are blind or partially sighted
- 7. Digitalising Care Homes
- Sheltered accommodation, digital health and care technologies and inclusion for over 55s

### 1: Health inequalities and addressing digital exclusion in Primary Care

A local Primary Care Network with a coastal community in the 10% most deprived Lower Super Output Areas and home to a significantly higher percentage of patients living with preventable illnesses, (Chronic Obstructive Pulmonary Disease (COPD), Diabetes type 2, dangerous drinking, and smokers) explored barriers to equitable health care and has taken action to mitigate against these.

They found barriers included inability to travel to the surgery; lack of trust in the NHS; and digital exclusion and low literacy. They took action to improve access to health and care for their population by supporting proactive home visits as an example by occupational therapists and building connections with other health and care partners such as drug and alcohol services; working with individuals like community support workers who were trusted by the community to promote health services; tackling poverty by training staff to recognise of signs of poverty and link patients into local fuel and food poverty initiatives. In addition to address digital exclusion, they worked closely with their local citizens advice bureau to provide mobile phones and ensured their health information was provided in plain language. They are now also part of the digital ambassador programme which will support local residents access digital health and care services through the NHS app at their practice.

### Angmering, Coppice and Fitzalan Primary Care Network, NHS Sussex

### 2: Tablet loans and building trust to address digital exclusion in Mental Health services

In response to COVID 19 a local Mental Health Trust, like many NHS services, moved online to support its service users and quickly recognised some of their service users needed extra support to be digitally included. Using a user- led design approach they set up a tablet loan pilot for two populations felt to be more likely to be digitally excludedforensic and rehabilitation services. They also utilised free data initiatives via a well-known mobile phone provider and provided digital guides and support hubs. In addition to providing access and skills another aim of the project was to build trust in digital and digital health care services in this population. Therefore, the devices were provided without software added including any health and care applications which may have led to mistrust about the motivation of the devise loan and lead to un-engagement with the project.

Although health and care apps where not added to the devices in advance this pilot did give individuals the opportunity to access health and care apps that could help their mental health and connect with family and friends. One participant even enrolled on an online college course. Of those responding to the evaluation individuals said they were more confident using digital, and benefits included 'filling up and occupying time', 'connecting and educational', 'life saving', 'helpful' and 'fun'.

At the end of the pilot individuals had to hand back their loan devices and were signposted to other device initiatives to continue their digital journey. This enabled the loan of the devises to other digital excluded service users with support from companies providing free sim cards.

Sussex Partnership Foundation Trust, NHS Sussex

#### *3: Digital Ambassadors: Sussex pilot*

The Digital Ambassador pilot is evaluating the impact of having a role in general practice at Primary Care Network (PCN) level with the aim of improving patients' digital confidence and raising awareness of the benefits of using digital health tools to support with health and wellbeing. Due to the Covid 19 restrictions in 2020/21, the pilot has now been extended for six months and will be followed by a full evaluation in January 2023 to determine next steps. In the second phase there are nine PCNs taking part.

Digital Ambassadors are general practice staff members who are enthusiastic about championing digital tools and services like the NHS App. They are employed across

administration and social prescriber roles and use various ways to reach out, raise awareness and meet with patients face to face to support them to register and use the tools. The NHS App provides an additional front door into the GP practice and supports self-care and health and wellbeing management by enabling individuals to view their health records online including GP and vaccination records; view and manage their repeat prescriptions; look up blood test and diagnostic test results; and receive online health advice through the NHS website. From a system perspective this, alongside the use of Online Consultation tools and remote monitoring healthcare tools, will reduce administration requirements for appointments, phone calls, and repeat prescriptions and free up appointments for more complex patients.

PCNs have expressed that their staff do not have capacity to show patients how to access digital healthcare tools – so it is 'really helpful to have someone who is available to support our patients to use digital health tools,' and it 'reduces burden on busy Reception and Clinical staff.'

Patients who have been supported by the Digital Ambassadors have commented that 'it's great to learn with someone face to face'.

Digital First Team, NHS Sussex

#### *4: Diabetes: sensor- based glucose monitoring systems*

Sensor based glucose monitoring systems have transformed diabetic management and blood glucose monitoring. They stop the need for regular finger blood glucose blood tests and enable constant monitoring of blood sugar levels helping to prevent peaks and troughs in blood sugar levels and the long-term health consequences of poorly managed diabetes. The sensors include an app accessed through smart phones which uploads results and alerts when blood sugar levels are out of range, and helps the person living with diabetes better manage their condition and diet by providing a constant view of blood sugar ranges over a 24 hour period.

Blood glucose monitoring systems are available on prescription but usually require the person living with diabetes (or a close carer- such as a parent for a child with diabetes) to have a smart phone that is close to the sensor and has constant connection to the internet, or alternatively intermittent access to a computer to download results. The level of interaction and benefits these sensors provide depend on the associated technology

available to share information presenting a potential access and affordability barrier to the full and equitable benefits of digital health care.

Some users of these sensors suggest the information can also be complicated and takes time to understand. Without appropriate guidance and support this could also present a barrier if someone has lower literacy or numeracy skills and lacks confidence in interpreting the information they are receiving and are expected to interact with.

The increasing number of digital home monitoring and screening apps across health and care have the potential to transform care and improve outcomes. However, if these technologies require additional infrastructure to function effectively- fully or partially-infrastructure that not everyone has access to this could lead to inequitable access to health and care.

### 5: The Connecting Lewes Research Project

The Connecting Lewes Research Project (2021) surveyed 148 people over the age of 50 living in Lewes, East Sussex, with the aim of understanding what was preventing uptake of digital communication technology in order to enable the provision of effective remote support for education, work skills, as well as combat loneliness, and poor mental health. Furthermore, to understand if assistance with tablets, phones or computers was helpful for older people, especially as a vulnerable group limited to restricted contact during COVID.

The results uncovered a divide in motivation to use technology, whereby those who had limited access to the internet cited cost as a barrier to adoption. Furthermore, those who did not have internet were more likely to be less motivated to use digital technologies and got less value from it. Compared with people who had internet connection, the people without internet found technology less appealing, and fewer thought technology could bridge the gap with distant friends and family.

Moreover, the study found that having internet access is associated with a higher number of weekly conversations and higher levels of company and help. For example, of all the people who had one weekly conversation or less, none had internet access. All the people without internet access agreed or strongly agreed with the statement "I don't understand technology and have difficulty using it". Without adequate internet at home, people are not able to access the appropriate technologies required for digital health and care. A lack of motivation due to inadequate access to internet, means those who are already unengaged with technology for communications purposes will not likely see the importance in using digital health and care technologies. Access to the internet is thus a great divider in people's digital experiences and potential uptake in digital health and care services in the home.

Jessica Hadjis van Thiel, University of Sussex

### *6: Digital accessibility for people who are blind or partially sighted*

Blind and partially sighted people, depending on their sight condition and level of sight, will have different methods of accessing digital information. Some people will still be able to use their vision whereas other people may require some form of additional access technology or software to aid them.

Additional access technology adds an extra level of complexity to the process. This is often overlooked by website and app developers and can lead to a blind or partially sighted person not being able to access the service/information.

There are different technology options available to blind and partially sighted people and what technology a person uses will depend on what devices they are familiar with using, what information they are accessing, their digital skills and its affordability.

Some examples of commonly used access technology/software for different devices are summarised in the following table. It is broken down into speech and magnification for both smart phones/tablets and computers/laptops (Windows and Mac).

Devices	Software (speech)	Software (magnification)			
Mobile phones (smart)					
IOS (iPhone /	Voice over	Zoom magnifier			
iPad)					
Android (phones	Talk back	Magnifier			
/tablets)	Blind shell 2 (simpler)				
PC/computer					
Mac	Voice over	Zoom magnifier			
PC	Jaws for Windows (expensive,	Magic (Professional use)			
	Professional)				

NVDA (free, limited support)	ZoomText (professional
Microsoft narrator (built-in)	use)
	SuperNova (professional
	use)
	Windows Magnifier (built-in
	to Windows)

For health and care digital services to be accessible and useable by blind and partially sighted people, websites, mobile apps, and integrated services (e.g. video consultations) will need to work with the most commonly used speech and magnification software.

Additional challenges faced by the blind and partially sighted community can include a lack of exposure to digital communications, perhaps due to not being in employment or not having such technology at home, or the skills and confidence to use it. Other challenges faced are adjusting and learning new technology due to software updates and the costs of keeping up to date in order to use the digital services.

Some services, such as "Be My Eyes" or "AIRA" (apps that enable a blind or partially sighted person to get human support via a video call) will be a solution (similar to how covid tests were made accessible) but for others, having a family member, friend or paid support might be the only option.

David Smith, Thomas Pocklington Trust

## 7: Digital care homes

Between 2021 and 2022 NHS Sussex (Ageing Well Directorate) supported a group of care homes in Bexhill with digital transformation. This included setting up digital social care records, encouraging care home staff to use NHS mail for secure healthcare communication, and connecting social care records to the NHS Sussex shared care record: 'Plexus'.

The Bexhill pilot successfully connected digital social care records to Plexus, allowing summary GP records and community trust information to be shared with care homes.

The pilot also determined that care home staff needed support in accessing NHS mail, and even when support was provided, a high turnover meant that staff were not always aware

that they could use NHS mail to order prescriptions or communicate with primary care. As a result engagement with NHS mail and initiatives such as the <u>care home ipad offer</u> was not consistent and required sustained training and support to embed digital changes and habits, and reap the benefits of those changes.

From a resident's perspective, the ability of care home staff to support residents to enable them to speak and connect with their family, friends, and loved ones, is very important. This pilot found that the training provided in care homes should include raising the awareness of the benefits of supporting care home residents in communicating with their family digitally.

During this pilot the project team occasionally found it challenging to communicate with care homes due to the workforces limited access to technology, sometimes relying on managers to bring in their personal laptops to attend online meetings with NHS staff.

Overall, the Bexhill pilot resulted in the development of a system outlining how care homes could be supported to use digital social care records and connect those record to 'Plexus' supporting ongoing digital transformation in care homes across Sussex. *Ageing Well directorate, NHS Sussex* 

# 8. Sheltered accommodation, digital technologies for health and wellbeing, and digital inclusion for over 55s

Since 2019, three studies led by the University of Sussex involving over 300 residents aged over 55, living in sheltered housing across the country, including Hastings, have sought to understand how residents use digital technologies for health and wellbeing in the home; how they gain and learn digital skills, and use health care online; and how they imagine health care will be provided in the future through digital technologies. The technologies included a digital Technology Enabled Care suite installed in social housing, assistive technologies (e.g. door openers), and consumer technologies (e.g. Fitbit watches, Bluetooth speakers, smart plugs and smart tablets).

Researchers found that the full functionality of the digital technologies studied is severely limited due to three significant factors: i) limited or non-existent provision of broadband in social housing (internet in communal areas only or the use of internet dongles or sim cards are not sufficient); ii) lack of peer support and peer-to-peer learning; and iii) lack of procedures to help develop and maintain an active digital environment (e.g. digital needs assessments, training).

Even in 'smart' sheltered schemes (with digital Technology Enabled Care suites installed) responsibilities for dealing with the use, troubleshooting and learning associated with digital technologies for health and care in a holistic way, falls outside the remit and usual responsibility of the multiple stakeholders operating in this space, resulting in a siloed and ad hoc approach. As a result digital technologies for health and wellbeing in sheltered schemes have limited ability to provide value for residents and can lead to active unengagement, resistance or rejection. This can mean they miss out on healthcare communication which is increasingly digital. Digital technologies for health care provision are also unlikely to work as expected (i.e. assume that it is possible to plug and play) in sheltered schemes without a sustained, holistic approach to creating an active digital environment that is user-friendly for residents.

Dr Ralitsa Hiteva, Dr Kate Simpson and Dr Cian O'Donovan, University of Sussex

		Digital service/pa	thway/te	echnology design objec	tives	
AWARENESS		CONSIDERATION		USE		POST USE
Our population is aware of digital health and care services/pathways and technologies and their relevance to them as individuals.	to devi equital benefit 2. will be digital regard skills. 3. can se with re service 4. can, an service 5. can, an	ation: itable access or can get suitable access or can get suitable access, and can interact with, a from digital health and care. enabled to access and interact with health and care safely and effectiv less of their literacy, digital or pers e the value of accessing and interact levant digital health and care. es/pathways/technologies. and does, trust in this e/pathway/technology. and does trust, what is happening to and how it is being used	ve and h ely onal acting	<ol> <li>Our service users:         <ol> <li>have reliable access and the internet wh to enable them to a interact with digital</li> <li>can access and inter health and care saf effectively</li> <li>have access to relia support whenever t</li> <li>value digital health will continue to use</li> <li>feel safe and know is safe when using and care</li> </ol> </li> </ol>	en they need it ccess and health and care eract with digital ely and able, trusted, hey need it. and care and it. that their data	Our population experience that they benefit from digital health and care and are motivated to continue using it
F	or each prog	ACCESSIBLE AND U ramme and across all pathways th	-	E PATHWAYS & TECHN e user will interact with, in		stive technologies
		<<<< GUI Design in information, er		and SUPPORT >>>>> and technological/pathw	ay support	
Enablers to awareness       Barriers to awareness       Pay special attention to:       Service/pathway/technology design to mitig digital exclusion						
Information available and accessible to target audience would benefit individual		populations Develop a com resources that care generally, pathway, techr		munication strategy and information raise awareness of digital health and and for the population this service, ology is designed for. Consider ort agencies, workforce.		

Appendix 5: Health and Care digital inclusion design/assessment tool

Enablers to access and affordability	Barriers to access and affordability	Pay special attention to:	Service/pathway/technology design to mitigate digital exclusion
Individuals have access to all the devices and apps that meet their needs. Access to connection, wifi, data, electricity, recognising access needs to be consistent for some health and care pathways.	No access, or limited access to technology, wifi, data, or electricity. Old / incompatible devises. Programmes with frequent updates/high specification requirements. Cost and personal priorities (essential items) Housing infrastructure and location (e.g. rural areas).	<ul> <li>People from no/low-income households</li> <li>People in insecure housing/homeless</li> <li>People with low literacy People with lower educational attainment</li> <li>Older adults</li> <li>Young adults</li> <li>People from NRS social grades D&amp;E</li> <li>People living in rural areas</li> <li>People who are disabled</li> <li>Limited or narrow users of the internet (Minority ethnic groups, <i>Women</i>, young adults)</li> </ul>	Ensure technology is fully useable and compatible with various devices, or provide alternatives Limit technology's specification requirements Consider cost, and how costs will be met by individuals or the system Consider how to meet requirements for service users with no/limited/unsuitable access and those who are unable to afford the relevant technology Work with other agencies to enable access to relevant technology (e.g. Libraries, voluntary sector) Ensure excluded populations, or those choosing not to engage in digital health and care are offered an equitable alternative.
Enablers to skills and support	Barriers to skills and support	Pay special attention to:	Service/pathway/technology design to mitigate digital exclusion
Individuals have the skills needed to engage with all necessary technology and pathways. Individuals have access to formal or informal (family /friends) support by trusted people available whenever this is needed.	Multiple and/or complicated technologies and pathways. Lack of awareness or access to trusted support (formal or informal). Lack of consistent support at each stage this could be needed (e.g. tech, app, update, when there is a problem).	<ul> <li>Older adults</li> <li>People with low literacy</li> <li>People with lower educational attainment</li> <li>People with disabilities</li> <li>Limited or narrow users of the internet (Minority ethnic groups, <i>Women</i>, young adults)</li> <li>Carers and workforce providing support</li> </ul>	Reduce the level of skills required to reduce support needs (e.g. plain language, single log on, accessible (physically and cognitively), interoperable, useable, intuitive) Consider how any support needs will be met across populations including formally and informally. Reduce complexity across all pathways, consider other pathways these service users will need to engage with.

	Dependency on informal support and lack of privacy, confidentiality, safeguarding concerns, reluctance to disclose, lack of consent or burden others*	People who may be at risk abuse	Ensure excluded populations, or those choosing not to engage in digital health and care are offered an equitable alternative.
Enablers to motivation	Barriers to motivation	Pay special attention to:	Service/pathway/technology design to mitigate digital exclusion
Individuals see the value of the digital product/service to them. Individuals believe that they have a 'real' voice and choice. Easy to use, accessible and require minimal support. Convenient - easier and faster access to healthcare services. Cost effective, reducing individual cost including travel time. Representative and personal	Technology or pathways too complex; too difficult to access, use or understand; too many steps (digital and other), multiple systems; doesn't meet individual need; added cost; not representative or sensitive; effort too much for the potential benefit.	All the population incl. carers and workforce but especially: Older adults People with lower literacy/confidence in their literacy People on lower incomes People in NRS social grades D&E	Ensure that pathways/technology is easy to use, convenient, and adds value to the individual. Reduce the amount of effort to engage in this service /pathway/technology for the individual. Ensure the value added to individual populations is explicit- (i.e. use comms and relevant examples) Ensure excluded populations, or those choosing not to engage in digital health and care are offered an equitable alternative.
Enablers to trust	Barriers to trust	Pay special attention to:	Service/pathway/technology design to mitigate digital exclusion
Trust in the system, service, pathway and technology. Individuals understand why and how data and technology is being used. Trust in human touch/clinical oversight maintained. NHS 'brand'	Lack of trust, which could be due to past experience, lack of human touch, lack of transparency over data, lack of perceived clinical oversight, lack of feedback. Not recognised or trusted technology/brand.	All the population incl. carers and workforce but especially: Older adults People with lower literacy/confidence in their literacy People on lower incomes People in NRS social grades D&E	<ul> <li>Build and maintain trust in the system, the service, the pathway, the technology and how data Is used.</li> <li>Ensure the service, pathway, technology is safe and maintains confidentially and privacy.</li> <li>Ensure transparency over clinical oversight, and build in feedback to digital interactions</li> <li>Ensure service users have a mechanism to feedback if/when there are issues, and access responsive care off the digital pathway when needed.</li> </ul>

Enablers to accessibility and	Barriers to accessibility and	Pay special attention to:	Ensure excluded populations, or those choosing not to engage in digital health and care are offered an equitable alternative. Service/pathway/technology design to mitigate
useability	useability		digital exclusion
The pathway/programme/technology is fully accessible to the whole population it is designed for including people with: •Visual, auditory, and speech and language needs •Physical, neurological and cognitive needs Incl. Dyslexia and neurodiversity •People with lower levels/confidence in their literacy •People whose first language is not English incl. cultural sensitivities •People reliant on different devices and assistive technology •Pathways and technology need to be easy to handle, easy to read/understand, easily integrated with assistive technologies	The pathway/programme/technology is not fully accessible to the whole population it is designed for. This may be because: The technology/pathway is too difficult to handle. It does not integrate assistive technology. The information is too complex The language is unreadable/untranslatable There are too many steps making it too complex	<ul> <li>People who are disabled <ul> <li>Physical</li> <li>Sensory</li> <li>Mental</li> <li>Cognitive</li> </ul> </li> <li>Older adults and ageing</li> <li>People with low literacy</li> <li>People whose first language</li> <li>is not English</li> <li>Cognitive accessibility</li> <li>People with lower educational attainment</li> <li>Carers and workforce</li> <li>People whose needs may change (life course)</li> </ul>	Ensure all service user information (however provided) is accessible to people with low literacy and cognitive accessibility needs e.g. plain language Ensure all information is translatable Ensure all technology and pathways interoperates with assistive technologies (for physical, sensory and cognitive disabilities) Ensure excluded populations, or those choosing not to engage in digital health and care are offered an equitable alternative.

### Appendix 6: Accessibility and Useability resource

Accessibility and Useability

The number of people reporting they had a substantial or long-term disability whether physical or mental increased to 22% of the UK

population in 2020/21. This includes up to 9% of children, 21% of working age adults and 42% of those at state pension age. Many more

people will have temporary disability. (gov.uk)

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Accessibility requirement	Factors to consider	% Population affected	Mitigation	Support
Literacy and language	Low literacy Health Literacy Digital literacy Numeracy Translation	In the UK 1 in 6 adults in England have very poor literacy skills; 4 in 10 people struggle with health content; 6 in 10 will struggle with health content that includes numbers <u>NHS Digital</u>	All patient facing communication must be plain language Language in technology must be accessible and easy to understand Plain language will be easier to translate Consider requirement and risk of individuals entering or interpreting numerical health data	Standard for creating health content - NHS digital service manual (service-manual.nhs.uk) https://www.healthliteracyplace.org.u k/toolkit/techniques/use-simple- language/ http://www.plainenglish.co.uk/medica l-information.html <u>https://pifonline.org.uk/resources/ho</u> <u>w-to-guides/using-plain-language-in- health-information/</u> <u>https://www.nhs.uk/about-us/health- information-in-other-languages/</u> <u>https://translate.google.com/intl/en- GB/about/languages/</u>

Cognitive accessibility	Illness Stress Dyslexia Neurodiversity (Autism/ADHD ) Learning disabilities Depression/An xiety Cognitive impairment Menopause Low literacy Poverty	10% of the UK population have dyslexia which can include dyscalculia (NHS) ADHD affects about <b>3-5% of</b> <b>children and 2% of adults</b> and is more common in males than females (4:1) <u>NHSE</u> <u>https://www.england.nhs.uk/north- west/wp-</u> <u>content/uploads/sites/48/2019/03/GM</u> <u>-wide-ADHD-guidance.pdf</u> Prevalence of ASD is 1% of the population <u>Zeidan et al 2022</u> Prevalence data is unavailable for other areas but relevant to most users of health services- illness and stress.	<ul> <li>Applied to the pathway, and any technology in combination:</li> <li>Limit no. of steps to follow</li> <li>Simple processes and procedures</li> <li>Explain medical jargon and acronyms in plain language</li> <li>Clear treatment plans and pathways</li> <li>Well framed services concepts and options (Wills &amp; <u>Bailey 2022</u>)</li> <li>Avoid "WALLs of TEXT"<u>writing for neurodiversity</u></li> </ul>	https://accessibility.blog.gov.uk/2016 /09/02/dos-and-donts-on-designing- for-accessibility/ UX Writing for Everyone: What Neurodiversity can Teach us -   UX Magazine
Physical disability	Dexterity Age related decline Immobility Tremors	Between 20%- 30% of working age and state pension age adults report issues with dexterity <u>Gov.uk</u>	Identification of individual needs. Various types of access to digital- keyboard, touch screen, nudge, size of technology, and motor skill requirements. Interoperability with assistive technology. Assessing changing needs as conditions may deteriorate.	Useful Accessibility Resources and Links   AbilityNet

Sensory disability	Reduction/loss of vision, hearing and sense of touch	Over 10% of state pension age adults report issues with vison and/or hearing. <u>gov.uk</u> One in five people aged 75 and over are living with sight loss; one in two people aged 90 and over are living with sight loss. Nearly two-thirds of people living with sight loss are women. People from minority ethnic communities are at greater risk of some of the leading causes of sight loss. <u>rnib</u> In the UK over 11 million people have hearing loss and around 900,000 have severe or profound hearing loss. NICE	Interoperability will commonly used screen readers on both Microsoft and Mac: (voice over, talk back, jaws, jaws 2, NVDA, blind shell, Microsoft narrator, magnification software)	Useful Accessibility Resources and Links   AbilityNet Welcome - 4Sight Vision Support https://www.bemyeyes.com/ Action for Deafness - NHS audiology service and support
Mental disability	Depression, anxiety, serious mental illness	1 in 6 people report experiencing a common mental health problem (like anxiety and depression) in any given week in England; 0.5 million adults are registered as having a SMI by their GP in the UK. <u>gov.uk</u> Depression is predicted to be the second leading cause of disability in people of all ages by the year 2020. The worldwide prevalence of depression is estimated to be 4.4% and prevalence in the UK is 4.5% <u>NICE</u>	Trust, support, awareness of services in different health settings, capacity to access services when unwell.	Health matters: reducing health inequalities in mental illness - GOV.UK (www.gov.uk) Useful Accessibility Resources and Links   AbilityNet