Digital Inclusion in Health and Care:

Lessons learned from the NHS Widening Digital Participation Programme (2017-2020)

By Dr. Emma Stone,
Peter Nuckley and Robert Shapiro

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Good Things Foundation

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Forewords

COVID-19 has changed the dial on digital. At home, at work, in our communities, in hospitals and care settings, digital has been central to our national response, and a lifeline during lockdown for those with the access, skills and confidence to benefit.

But too many are still locked out. If we don't act now, millions of people will be left further behind with deeply damaging consequences for health inequalities. Digital (access, skills, confidence) has become a social determinant of health.

Our Widening Digital Participation programme completed in March 2020 and the lessons learned shared in this report could not be more timely.

I'm proud of how much we've achieved through both phases of the Widening Digital Participation partnership with NHSX, NHS Digital and NHS England. By putting co-design, communities and collaboration at the centre, we've learned so much about how to help people benefit from digital health, including those who already face barriers to accessing health care.

Our new model of 'digital health hubs' - tested and evolved through a series of pathfinders - stands out as a way to improve digital health literacy, and prevent digital exclusion from widening health inequalities. This is something we can - and should - build on. We need a national network of community-led local digital health hubs as part of a coordinated national strategy for digital health and inclusion.

A world-leading digital health service will only deepen inequalities if we don't act on digital inclusion. I hope this report inspires and encourages us all about what can be achieved, and what we still need to do, so that everyone - and every community - can benefit from digital for their health and wellbeing.

**Helen Milner, OBE,
Group Chief Executive**

Technology, done right, can be an enabler and offer people, particularly those who find it difficult to access traditional services, a more convenient and a better experience of using NHS services to manage their health and care.

Our ambition from the start, with our partner Good Things Foundation, was to truly understand the barriers for people with accessing and using digital health services.

Our Widening Digital Participation pathfinder model was based on principles which guided us to go to where people are - whether that was a GP surgery, a homeless shelter, a dementia support group or a cancer support network. Being there, talking to people, drinking tea and learning about their lives allowed us to gain trust and valuable insights into what they really need. Partnership with the community is also essential - local charities, NHS organisations, local government and, of course, people themselves. This is how to design and deliver digital health services that people will want to use and are able to access.

Our local digital health hubs are a great example of the success of joint-working and co-design. Our prototype digital health hub was a joint project in Nailsea - with the local council, CCG, medical practice, library, Healthwatch, Citizens Advice, disabled people's groups and selfcare groups. Run by local volunteers, 65 High Street hub helped people with building digital confidence, signposting to local health activities, and motivating healthy behaviour change. Over one year on, it is still going strong!

If we, as NHS commissioners, policy makers and designers of digital health services and tools, can do just do some of the things recommended in this report and make a commitment to invest in leaving no one behind, then hopefully we can start to narrow the gap of health inequalities, and help people benefit from the choice and convenience they offer.

Nicola Gill, Programme Lead for Widening Digital Participation, NHS Digital

Executive summary

Good Things Foundation worked with NHSX, NHS Digital, NHS England and local partners in health, social care, and community sectors to widen digital participation in health and care. In the context of COVID-19, the lessons learned could not be more timely.

The Widening Digital Participation programme completed in March 2020 - just as the country went into lockdown following the outbreak of coronavirus. While the NHS Long Term Plan had already set a vision for mainstreaming use of digital in health care, COVID-19 triggered an immediate rise in the use of online health information and services. In March 2020 alone, online consultations doubled from around 900,00 to over 1.8 million (Bibby & Leavey 2020).

In September 2020, NHS England asked NHS leaders to review service use and develop digitally-enabled care pathways to increase inclusion, ensure all patients receive the same level of access and care regardless of their digital preferences, and "ensure it does not affect health inequalities for others, due to barriers such as access, connectivity, confidence or skills" (NHS England 2020). Lessons learned from the Widening Digital Participation programme could not be more timely.

The Widening Digital Participation programme aimed to ensure more people have the digital skills, motivation and means to access health information and services online. Phase 1 (2013-16) focused on improving digital health literacy in communities. Phase 2 (2017-20) used co-design to find points in health and care systems which could be improved with digital and community interventions.

Phase 2 supported 23 pathfinders, each with a different focus reflecting local needs and partners, from homelessness to self-care of long-term conditions. Partners included Clinical Commissioning Groups, GPs, hospitals, local authorities, care homes, and voluntary and community sector providers.

Another 5 pathfinders and 22 mini pathfinders evolved a model of community-led local 'digital health hubs', which emerged as a promising way to improve digital health literacy and inclusion. Phase 2 Pathfinders supported 21,178 people.

During the programme, a further 166,162 people were made aware of digital health resources through the Good Things Foundation network of community partners; and 53,173 people improved their digital health literacy through Good Things Foundation's free online learning.

When asked, 83% of people using Learn My Way said they felt more confident about using online tools to manage their health (Good Things 2019/20). When people who completed Learn My Way health courses were asked 3 months later, 33% said they made fewer visits to their GP (average 4.8 visits saved) and 14% said they made fewer visits to A&E (average 3.1 visits saved) (Good Things 2019/20).

A Return on Investment calculation undertaken for Phase 1 (which focused on building digital health literacy through community organisations) identified a potential saving to the NHS of an estimated £6 million a year, representing a £6 return on investment for each £1 spent on the programme in its third year.
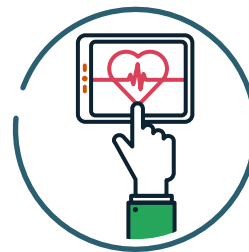
Phase 2 delivered...

23 locally-led pathfinders including digital health literacy, dementia, cancer, refugee health, social care

5 pathfinders and 22 mini pathfinders evolved a model of community-led local digital health hubs

21,178 people supported, including 824 people in co-design, and 1,350 digital champions

166,162 people made aware of digital health through Good Things' network of community partners

53,173 people improved their digital health literacy through 'Learn My Way'

£6 for every £1 Return on Investment for Phase 1 of Widening Digital Participation, which focused on building digital health literacy via community organisations

Lessons learned and recommendations

The programme report shares insights, practical pointers and summarises lessons from pathfinder evaluations. Across the diversity of pathfinders, eight key messages and areas for action emerge.

1 Recognise digital access & skills as a social determinant of health

Being able to afford internet access and having the digital skills to use the internet safely are now essential for education, employment, income, social participation, and access to information and services. All are wider determinants of health. COVID-19 has further exposed the digital divide - the correlations between digital exclusion, social and economic disadvantage - as well as putting the spotlight on intersectionalities between ethnicity, poverty, poor health, and racial discrimination.

Recommendations:

- Recognise digital access, skills and confidence as a social determinant of health.
- Improve national data on the links between digital inclusion, health care and outcomes.

2 Co-design digital health services

Co-design is a method of involving patients or the public, practitioners and decision-makers in designing services. It is about finding the best solution with people; not necessarily making something new. Digitalisation always needs to be seen as part of a service or solution; not as the whole solution. Digital services can amplify existing barriers to accessing health care, unless action is taken to reduce these.

Recommendations:

- Patients should be able to use what works for them - whether digital, physical, or a blend.
- Co-design with patients should be at the heart of a digitally-enabled NHS; it should always include co-design with those who have low digital skills and face barriers to health care.

3 Improve digital health literacy in the population

Strategies to improve health literacy have been identified as important for reducing health inequalities. As digitally-enabled health care and information becomes mainstream, this makes population digital health literacy a priority. This includes supporting people to navigate the health and wellbeing risks of the internet and social media, and helping people with low digital skills to understand how their health data is used.

Recommendations:

- Improve population digital health literacy, and support safe and healthy internet use.
- Improve people's understanding of how their health and personal data is used.

4 Develop 'digital health hubs' to improve inclusion

Community 'digital health hubs' emerged as a practical way to build digital health literacy and improve access to health and wellbeing. Building on lessons from three pathfinders, the approach was further tested in five pathfinders and 22 'mini' pathfinders. A digital health hub is: trusted and embedded in the community; responds to people's interests; reaches poorly-served groups; builds digital and health literacy together; supports wider wellbeing as well as access to digitally-enabled health care. They build bridges between the community sector and health systems, helping to reduce inequalities.

Recommendations:

- Further test and scale digital health hubs as community infrastructure for inclusion.
- Develop commissioning frameworks which support the role of community sector partners.
- Establish a national community of practice for digital health hubs.

5

Build trust and relationships with poorly-served groups

Trust, and the time to build relationships, featured highly as an ingredient for success, especially in supporting people with severe and multiple disadvantages. Trusted people could help to rebuild the relationship with health services, and mitigate the barriers to accessing online health services. Being supported by 'people like me' and 'in my language', and 'exploring together' also helped to build digital health literacy and confidence.

Recommendations:

- When commissioning for digital health inclusion, recognise the time needed to build trust.
- Train and support peers to be digital champions for health and care.

Harness the benefits of digital for health and wellbeing

6

Across pathfinders, digital inclusion brought practical, emotional, social and wellbeing benefits to those who had been digitally excluded or only used digital in limited ways. With older people, carers, people dealing with homelessness, substance abuse and people seeking asylum, digital inclusion opened up new and different conversations about health and wider wellbeing. Some people with low trust in formal services felt able to use the internet to access reliable health information.

Recommendations:

- Support people to try out different devices and assistive technologies.
- Include information about how to improve accessibility when training digital champions.

7

Improve digital skills in the health and care workforce

A lesson across pathfinders was not to make assumptions about the level of digital skills, confidence and motivation among the workforce. Reluctance from staff to use digital tools also reflected concerns about service quality and job security, as well as organisational and practical issues. Providing support to staff delivered positive results, with added value where strategies to build digital skills and confidence included both staff and services users together.

Recommendations:

- Build digital confidence and motivation of staff, following Health Education England's lead.
- Train, support and build a network of digital health champions in a service or locality.

Embed digital inclusion in health, care and wellbeing strategies

8

Successful partnerships improved the local health, wellbeing and digital inclusion infrastructure. They strengthened bridges across sectors, working together to improve access to devices and digital inclusion support, creating networks of peer and volunteer digital champions, improving referral routes and cross-agency working, and building on existing community sector assets. In Leeds, the dementia pathfinder was integrated into a city-wide collaborative programme, 100% Digital Leeds, as well as the Health and Wellbeing Strategy, and Health and Care Plan Outcomes from the start.

Recommendations:

- Embed digital inclusion and digital health literacy in local health and wellbeing strategies.
- Builds on community assets and collaboration across health, care and community sectors.

Introduction

Good Things Foundation has been working with NHSX, NHS Digital, NHS England and local partners in health, social care, and community sectors to improve digital participation in health and care. The NHS Widening Digital Participation programme completed in March 2020 - the month when the country went into lockdown following the outbreak of coronavirus. Since then, the national and community response to COVID19 has revealed digital as a universal need. Digital participation has become essential for our lives, for our health and wellbeing.

COVID19 and digital health services

Through this pandemic, digital technologies have been at the heart of our collective national response to COVID-19. In homes and communities, digital technologies have enabled children and adults to stay safe, connected and informed; to learn, earn and exercise at home; to manage stress and anxiety; to mitigate the risks of social isolation and loneliness. In hospitals, GP practices and care settings, digital technologies have enabled the NHS, social care and public health authorities to continue serving the population. From NHS-approved apps to GP online and video consultations - there has been a significant increase in the population's use of digital health services.

Before the pandemic, 66% of all adults had never used the internet or apps to manage their health, rising to 79% among those with low digital engagement (Lloyds 2020). According to the annual GP Patient Survey, awareness and use of online bookings for GP appointments had increased to 48% and 19% respectively in 2020 (compared to 44% and 15% in 2019); similarly for online ordering of repeat prescriptions (44% and 19% respectively, compared to 41% and 16% in 2019) (Ipsos Mori 2020).

Following the outbreak of COVID-19, the use of digital in primary care changed dramatically. In March 2020 online consultations doubled from around 900,00 to over 1.8 million (Bibby & Leavey 2020). In June, a survey of GPs found over 94% were providing online consultations, and 88% felt greater use of remote consultations should be retained longer term (BMA 2020). Research into the patient experience of remote and online consultations during lockdown finds it has been beneficial for many (including those previously sceptical); has created barriers for some; and some of those barriers can be reduced through seeking feedback and improving practice (Healthwatch et al 2020).

The commitment that every patient would have the right to be offered digital-first primary care by 2023-24 was already in the NHS Long Term Plan and reflected in targets in the GP Contract. No-one could have predicted how soon this vision would be realised.

When it comes to digital health services, most of the interest and investment has been directed into technology and data, and the digital transformation of institutions. Gradually, attention has turned to digitally upskilling the health and care workforce (RCGP 2019, HEE 2018). Far less attention has been afforded to the digital access and capabilities of citizens, patients and carers.

Healthtech innovations (such as NHS content being available on Amazon's Alexa devices) can be life-changing for those who can and want to use them. But for people who can't afford home broadband or devices, or have low digital skills, such innovations will not touch their lives, improve their health or support their interaction with the NHS.

More broadly, the pandemic has raised questions around the links between digital exclusion and health inequalities. People more likely to be shielding and self-isolating have been among those more likely to be digitally excluded. People with no or limited internet access and low or limited digital skills are more likely to be over 70 years old, living in low income households, have lower literacy and educational attainment, and have a disability or long-term health condition. It has taken this pandemic for health and care sectors to recognise the scale, nature and significance of digital exclusion.

Digital exclusion and health inequalities

Ten years on since the Marmot Review into health inequalities, the Institute for Health Equity found that life expectancy had failed to increase for the first time in more than 100 years, and even declined for the poorest 10% of women (Marmot 2020).

There is a well-evidenced social gradient in health outcomes. People in the bottom 40% of the population by household income are almost twice as likely to report their health as 'bad' or 'very bad' compared to those in the top 20% (Tinson 2020). In England, there is also a north-south divide. Populations with below-average healthy life expectancy and below-average incomes are largely in local authorities in the north of England. COVID-19 has also shone the spotlight on health inequalities and systemic barriers faced by Black, Asian and minority ethnic communities (BMJ 2020).

According to analysis by the ONS (2017), over a third of 25- to 64-year-olds in the lowest healthy life expectancy (HLE) areas were economically inactive because of disability or a long-term condition. The lowest HLE areas had a greater proportion of adults with no qualifications at all (12.8%), which was 50% higher than in England overall (8.6%) and nearly three times higher than in the highest HLE areas. Nearly twice as many people died from causes considered preventable in the lowest HLE areas compared with the highest. They were more than twice as likely to be long-term unemployed; and more likely to be in routine or manual occupations, unemployed, economically inactive.

Currently, there are no national datasets which track the direct relationship between digital exclusion, access to digital healthcare, health outcomes and health inequalities. However, there is evidence of correlations between digital exclusion and poverty, disability, unemployment, and low educational attainment (Ofcom 2020).

In the UK, an estimated 9 million people are unable to use the internet independently; a further 2.7 million can use the internet independently but lack all the essential digital skills for life, as set out in the UK Government's Essential Digital Skills framework (Lloyds 2020). Disabled people and those with long-term conditions are 23% less likely to have the essential digital skills for life (Lloyds 2020). Among working-age adults, those in the lowest socio-economic groups are more than three times as likely as those in the highest socio-economic groups to not use the internet or (if they do use it) to be 'limited users' who use the internet for only a few tasks (Ofcom 2020).

In the UK, an estimated **9 million people** are unable to **use the internet independently**

A survey for the Health Foundation illustrates the digital divide. When asked whether they would download a COVID-19 contact tracing app, 71% of people with a degree said they would download the app, falling to only 38% among those with no formal qualifications; while 17% aged over 65 years old reported that they did not have a smartphone (Health Foundation 2020). Analysis of GP Patient Survey data also suggests lower awareness and use of online GP services among people from some Black, Asian and minority ethnic communities (GPPS 2020).

Through lockdown, digital has become essential for education and employment, income, social support and participation, as well as accessing health, welfare and other services. The digital divide, alongside systemic barriers faced by Black and minority ethnic communities, have been identified as areas of inequality which have risen to prominence and require addressing for a healthier future (Bibby & Leavey 2020). Digital inclusion/exclusion has become a social determinant of health.

About the NHS Widening Digital Participation programme

The Widening Digital Participation programme aimed to ensure more people have the skills, motivation and means to access relevant health information and services online. The programme focused on people at greater risk of health, socio-economic and digital disadvantage. For these groups, digital can provide access to relevant information, to health and care professionals and peer support. Digital technologies can also help people to manage long-term conditions, and support improvements in their wellbeing and health outcomes.

Phase 1 of the NHS Widening Digital Participation Programme ran from 2013 to 2016 to improve digital health literacy in local communities through a 'blended learning' model of community-based learning and online learning, partnering with community organisations with the relationships and reach to those who need support.

Phase 2 was a partnership between NHS Digital and Good Things Foundation, and ran from April 2017 to March 2020. Phase 2 took a very different approach. Whereas Phase 1 focused on improving digital health literacy, Phase 2 did not assume that lack of digital skills was still the main barrier, but instead explored where the barriers lie and how they could be tackled. So in Phase 2, support was provided to locally-led pathfinders to find points in health and care systems which could be improved through digital technology and community interventions. Design thinking and co-designing with patients and citizens, decision-makers and practitioners was at the heart of this approach.

Alongside this, Good Things Foundation sustained the legacy from Phase 1: making available free online learning content on using digital for health through the Learn My Way platform; promoting use of the internet for health and wellbeing through awareness raising campaigns and through the wider network of community partners or 'online centres' supported by Good Things Foundation.

NHS Widening Digital Participation Programme - Phase 2

The programme was funded by NHS Digital and delivered by Good Things Foundation (2017-20).

- **Pathfinders**
  - **23 pathfinders** (12 months) to test and learn how digital technology and community interventions can improve health and care
  - **5 pathfinders** (12 months) to evolve the digital health hub model and build on learning to date, focused on groups facing deep social and economic exclusion
  - **22 mini-pathfinders** (6 months) to test the emerging digital health hub model through the Good Things Foundation network of community partners

- **285,164 people** in total were reached, engaged or supported through Phase 2 (2017-20)

- **21,178 people** were supported through the Phase 2 Pathfinders. This includes:
  - **824 people** involved in co-design, user insight and co-creation sessions
  - **1,350 people** trained as digital health champions or peer mentors

- **263,986 people** were reached, engaged or supported through the Good Things Foundation network of community partners, online resources and campaigns, This includes:
  - **53,173 people** who improved their digital health literacy through Learn My Way
  - **166,162 people** who were made aware of digital health resources through their local 'online centre'
  - **44,651 people** who were reached through awareness raising campaigns.

Pathfinders were co-designed and delivered by local consortia, variously including Clinical Commissioning Groups, GPs, local authorities, care home providers, voluntary sector organisations and community groups. With support from Good Things Foundation's Service Design team, each consortium identified points in health and care systems, products, processes and patient journeys which could be improved through digital technology and community-based interventions. Pathfinders usually ran for 12 months and were funded by a grant from the programme to contribute towards costs incurred. While each pathfinder was unique, all were supported to go through a series of five steps and draw on co-design principles.

NHS Widening Digital Participation Pathfinder Model

Step 1: User needs

Spend time with people to understand their needs, not wants.

Step 2: Stakeholder needs

Understand their pressures, expertise, view of the current system and how things can improve.

Step 3: The Change

Create recommendations to try out. This could be a new service or a tweak to a service.

Step 4: Iterate

Try it for a while. Take stock. Find out what is working and what isn't, then iterate.

Step 5: Deliver and evaluate

Capture impacts and insights along the way.

Co-design is a method of involving users, decision makers and practitioners in the process of design. Users are the people who will be most directly affected. Often this is a patient but users can also be a carer, health or care or community worker. The approach used in the programme is summarised in the 'Co-design How To Guide'; it informed the NHS Digital Service Manual's Design Principles.

Good Things Foundation Co-design Principles

1. **Design with people, not for them:** The premise of co-design is including those who will be affected most by decisions. They are the experts in their lives.

2. **Go where the people are:** Conversations are more honest when people feel comfortable and safe. Spend time where they spend time. Shift the power dynamic: avoid formal buildings.

3. **Relationships not transactions:** Health is an emotive subject. People's relationships with peers, professionals, digital tools and their environment must be taken into account.

4. **Work in the open:** Share your learning. Share your work. Be transparent in your design decisions. Have confidence to tell people why something worked or not. It will help others.

5. **Understand underlying behaviour:** Look beyond immediate causes to understand the many different factors behind behaviours: personal, social, cultural, economic. Be conscious of, and check, the assumptions you make.

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

Through the programme, Good Things Foundation supported pathfinders that explored ways to support people from diverse backgrounds and with different needs. This included adults experiencing complex and multiple disadvantages such as homelessness and substance abuse; older people with care and support needs; spouse and family carers of people living with dementia; young people in areas of high ethnic diversity and deprivation; and adults of all ages living with long-term conditions such as cancer and multiple sclerosis.

The programme also involved taking the first steps to test a model of 'digital health hubs' – a model which emerged through the learning from three early pathfinders (in Nailsea, Sheffield and Hastings). The 'digital health hubs' model was tested further through five pathfinders (12 months) and 22 mini pathfinders (6 months).

The Widening Digital Participation programme was focused on England, but the lessons have relevance to other UK nations and jurisdictions, as well as internationally. In Wales, for example, the Digital Communities Wales programme is delivered by Wales Co-operative Centre, supported by Good Things Foundation. Significantly, it is jointly funded by the Department of Communities and Regeneration and the Department of Health and Social Care.

About this report

This report pulls together lessons learned, summarises achievements, and makes recommendations. It draws on evaluation reports, practical 'how to' guides, case studies and write-ups that have been developed and shared throughout the programme. This includes an independent evaluation of the 'digital health hubs' strand - undertaken by WSA Community Consultants, commissioned by Good Things Foundation as part of the programme. All programme resources and outputs are freely available on the Good Things website and listed in Annex 1.

The programme completed in the same month as the coronavirus outbreak took hold in the UK. The lessons and recommendations reflect the hyperlocal, face-to-face nature of the programme, which was rooted in relationships and communities, alongside digital tools. Yet the overarching message could not be more timely and urgent. Coordinated action is needed now to prevent health inequalities from widening further as a result of digital exclusion, and to support all adults - young and old - to develop the digital and health literacy they need to benefit from digital health and care services.

Design
with people,
not for them

Chapter 1

Improving digital health literacy

Rapid expansion of the internet and developments in digital technologies, the Internet of Things, robotics and machine learning require a shift in how we understand health literacy. The Widening Digital Participation programme (Phase 1 and Phase 2) has explored how to improve people's abilities to find, understand and use digital health and care services.

What is digital health literacy

Health literacy describes the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health. Strategies to improve health literacy have been identified as important tools to reduce health inequalities. This is because the most disadvantaged groups are at more risk of limited health literacy, and are known to have the poorest health outcomes (Public Health England 2015, NHS England 2018).

As health information has gone online, the concept of e-health literacy (and tools like e-HEALS) has developed. People need to be able to read, use devices, search online for and understand e-health information, and put it into context.

Digital health literacy is a term that better reflects the breadth of ways in which digital technologies and data are now being used for health, care and wellbeing. Digital health is evolving all the time - not only through websites and apps, but the evolution of the 'Internet of Things'.

Digital health includes:

- Online health information, such as using the NHS website or condition-specific websites
- Online health safety, being aware of fake health information or health data scams
- Online health transactions, such as booking or confirming appointments, ordering repeat prescriptions
- Video or online GP consultations
- Apps, including the NHS App, and other apps for health improvement, mental wellbeing and healthy lifestyle behaviour change
- Internet of Things and wearable technologies for fitness, healthcare, and emergency support, including self care of long-term health conditions
- Online peer support forums, e.g. for people living with long-term conditions and carers
- Understanding patient data, and how it is used.

Some people will have good health literacy but limited digital access, skills and confidence (more likely among older adults). Some will have poor health literacy but good digital skills (more likely among younger adults). Some people will lack both digital literacy and health literacy. Low literacy and low English language proficiency are additional barriers (Stone et al 2020).

The UK Government, in consultation with industry and civil society, has defined the essential digital skills needed for life and work (DfE 2019). Through the Widening Digital Participation programme, we have made important steps towards surfacing the essential digital skills needed for health and care.

Applying the Essential Digital Skills to Health

Communicating

- I can use an online or video GP consultation
- I can be a member of an online community to support my health, wellbeing or self-care

Handling information and content

- I can evaluate health information, and see that it may, or may not, be reliable
- I can use search engines to find relevant health and care information

Transacting

- I can make a GP appointment online
- I can order a repeat prescription online

Problem solving

- I can use the NHS website to help me decide whether I need to see a GP or go to A&E
- I can use the internet to find local support for health, wellbeing and other activities

Being safe and legal online

- I can recognise suspicious links to protect myself from health and medical scams
- I can keep my NHS app account secure

Social media and the internet carry risks, including emotional, psychological and health risks. Helping people to identify and mitigate these for safe and healthy internet use is essential. Improving people's understanding of how their health and personal data is used is also of growing importance. This is not only about NHS patient health records, but also personal data collected by commercial providers through wearables, apps and the Internet of Things.

Case study:
Roy's story

Roy, who is retired, started with virtually no confidence in using the internet. He took part in digital skills classes offered by Digital Champions in Thanet. Roy covered the basics and wanted to keep learning. He was supported to use a range of digital tools.

> *"I've found two health apps - one is a patient access app which I've joined, which means I can manage my medication which I need every month, and manage my appointments online. My medical records, I currently don't have access to them, but I will get them. That way I can go anywhere and my medical records are easily accessible for anyone who needs to see them, such as GPs and other hospitals."*

> *"I even have an app that tells me how many people are in the waiting room of each hospital in the area. I used it on Boxing Day, as I needed to go to A&E. There was one hospital with 34 people waiting and another hospital with only 1. So I went there and went straight through to see the doctor."*

Now, Roy is not just managing his physical health more effectively, but his financial health too.

> *"I am also able to do my banking online too. I can't use the branches any more, so I do everything online and my bank gives me 5% interest - so it's actually quite good for me."*

Roy is also enjoying the social aspect that comes from the classes and the skills learned there, using Facebook Messenger and WhatsApp to keep in touch with the group, as well as with family.

How to improve digital health literacy

Phase 1 of the NHS Widening Digital Participation programme focused on improving digital health literacy (Good Things Foundation 2016). This was primarily done through developing free online learning content relating to health, hosted on the Learn My Way platform, and providing community-based and face-to-face support to enable people to use these resources. The online learning content was developed for people with lower literacy levels and low or limited digital skills. As well as covering the essentials about using devices and the internet, the courses include how to use the NHS website, and how to do digital health transactions using GP online services. These courses are designed to give learners more confidence in managing their own health and making the most of the online health services available.

Local face-to-face support was provided through building a Digital Health Information network, which harnessed the existing Good Things Foundation network of community partners ('online centres'). Participating community partners were grant-funded to offer face-to-face support to help people improve their digital health skills, using the online learning resources. This was often delivered through training local digital health champions to raise awareness of digital health resources and help people build confidence. Over three years, the programme achieved significant reach and impact.

Improving Digital Health Literacy

Phase 1 of the Widening Digital Participation programme funded by NHS England and delivered by Good Things Foundation (2013-16) achieved reach and impact:

- **221,941 people** supported to use online learning to build their digital health skills
- **56%** went on to find information on the internet about health conditions, symptoms or tips for staying healthy
- **54%** said they would now go to the NHS website first for non-urgent medical information
- **8,138 people** trained as volunteer Digital Health Champions to promote digital health tools.

By helping people to move non-urgent medical queries from face-to-face channels to online ones, the programme evaluation identified a potential saving to the NHS of an estimated £6 million a year, representing a £6 return on investment for each £1 spent on the programme in its third year.

In Phase 2, improving digital health literacy has been an important component in several of the pathfinders, especially those developing the 'digital health hubs' model. It has also been supported through the Good Things Foundation's network of community partners. During Phase 2 of the programme, 53,173 people used Learn My Way to improve their digital health literacy.

In a recent survey of people using Learn My Way, 83% of people who used the health courses on Learn My Way health said they felt more confident about using online tools to manage their health (Good Things Foundation Learner Survey, 2019/20). Building digital skills also supports wider wellbeing. After completing courses on Learn My Way, 80% of people reported improved general self-confidence; 51% said they felt less lonely or isolated; 65% said they felt happier as a result of having more social contact (Good Things Foundation Progression Survey, 2019/20).

"I started Learn My Way a few months ago and still look at it ... More confident to access health services – about my health but want to learn more..."
Participant, digital health hub

The concept of 'digital health hubs' is discussed separately, but it is worth setting out here the different ways in which community-based digital health hubs can support digital health literacy alongside reducing barriers to accessing health services, and building bridges between community groups and organisations, and local health and care services.

How digital health hubs can improve digital health literacy

1. Support people to do free online learning

Such as doing the free Learn My Way courses on 'GP services online a how to guide', 'NHS website a how to guide' and 'Online safety and security'.

2. Support people to find online health information and support

Such as finding and using the NHS website, condition-specific websites and relevant online peer support (e.g. condition-specific forums, carers forums).

3. Support people to do online health transactions

Such as booking a GP appointment online, ordering a repeat prescription, or using video calling so they can do a video GP consultation independently or with support.

4. Support people to find and download trusted health apps

Such as registering to use the NHS App, finding NHS-approved or other trusted health apps, including apps which support healthy behaviour changes and wellbeing.

5. Support people to use the benefit for wider wellbeing activity

Such as using the internet for their interests; using social media and online video to connect with family and friends; recognising the wellbeing risks of social media; and searching online for locally available support, activities and groups.

6. Signpost people to local health and wellbeing support

Making referrals to locally available support or services, using social prescribing link workers, and using digital champion knowledge of locally available activities and groups.

Chapter 2

Digital Health Hubs in Communities

Through the Widening Digital Participation pathfinder programme, the model of 'digital health hubs' emerged as a practical approach to improve digital health literacy and support people to access relevant support (online and in their area). With the right conditions, digital health hubs can also build bridges between the community and voluntary sector and local health systems. This section describes the evolution of digital health hubs, lessons learned and the potential for development.

Discovery phase

A pathfinder in Nailsea was the prototype for the digital health hub model. It was led by Nailsea Town Council and supported by a range of local health and voluntary sector organisations, including the local Clinical Commissioning Group, medical practice, library, Healthwatch, Citizens Advice, disabled people's groups and other self-care groups.

Nailsea Town Council and partners tested whether creating a new community space – 65 High Street - could use community engagement to improve local health and wellbeing. This reflected existing evidence and guidance on community engagement: using local collaborations to build initiatives focused on improving general community wellbeing; using peer workers or volunteers in affecting individual behaviour change (NICE 2016).

A design workshop with local stakeholders set a vision. A 2 day pop-up shop to test this shaped the physical space and the support offer. 'Openness' was the core principle: a place where everyone is welcome and feels free to ask for support - whether that is about using digital, health conditions, wider wellbeing or local community life.

Through conversations with users, 65 High Street learned how best to introduce digital health. One lesson was that active conversations about digital health were needed: people may not see digital technology as helping with their health. This reflects wider evidence about digital behaviours. Before the pandemic, 66% of adults had never used the internet or apps to manage their health; this was even higher - 79% - among those with low levels of digital engagement (Lloyds 2020).

Nailsea's 65 High Street became a focal point for community engagement, digital inclusion, healthy ageing and wellbeing. Peers and volunteers played a key role: listening, sharing public health knowledge, building digital confidence, signposting to local activities, and motivating healthy behaviour change. Over one year on, it is still going strong as Nailsea's digital community hub. It is informal, volunteer-run, offers technology access and guidance, and supports health and wellbeing - broadly defined to respond to what people need.

Another early prototype was a pathfinder in Sheffield, which was led by a GP medical practice. The Sheffield pathfinder tested approaches for using social prescribing for digital health inclusion. Their hypothesis was that if users have access to digital health support as part of a conversation about how to meet lifestyle goals, then they are more likely to engage with information about how they can use the internet to support these goals. While the Sheffield pathfinder was led by a GP practice, the conversation about lifestyle goals and digital health was delivered by a local community organisation (a member of the Good Things Foundation network of community-based digital inclusion partners).

> *"I think that the service Heeley Development Trust provides is brilliant and I'd recommend any other patients to pop along to the Digital Surgery and give it a go."*
> Service user

> *"My mental illness is a lot better and I'm more stable. I've found a new me and I don't want to go back to where I was before, but if I were to, I'm now armed with more resources and have more friends and more people that I can ask for help and support."*
> Service user

The positive partnership between a GP practice and a community digital inclusion partner in Sheffield prompted further exploration in the programme of the role that the Good Things Foundation network of community partners might play to support digital health literacy and inclusion in communities.

Testing the potential for scaling

Building on lessons from Nailsea, Sheffield and also the Seaview pathfinder in Hastings, the Widening Digital Participation programme tested the emerging approach further. The hypothesis was that dedicated community locations, with trusted people on hand to guide, can help socially and digitally excluded people to improve their online skills and access relevant information and tools (online and in their local area) to improve their health and wellbeing.

Five pathfinders were supported to establish a digital health hub over 12 months, focusing on people who experience multiple disadvantages and barriers to health. This included a hub supporting refugees and asylum seekers, and two hubs supporting people with substance addictions. A further 22 community digital health hubs were supported for six months, following a call through the Good Things Foundation network.

A commissioned evaluation of the digital health hubs pathfinders identified positive impacts in people's engagement with digital health and wider wellbeing; and strengthened partnerships between community and voluntary organisations and parts of the local health system (see Annex).

People received support to:

- Do digital health transactions, such as using online GP systems and other health platforms

- Get reliable online information about a health condition

- Find information and ideas to support their wellbeing, online and in their area

- Improve their digital skills and confidence more generally, finding out about digital resources.

The five digital health hubs supporting people who face multiple barriers recorded 697 attendances over the 9 months to December 2019. They also reported a total of 37 different community groups accessing their digital health hub offer. The 22 smaller digital health hubs recorded 626 attendances over the 6 months to February 2020.

Table 1: What people attended their local digital health hub for

Digital health hubs - complex lives	Community digital health hubs
Based on records collected over 9 months, people attended for: • getting help with developing digital skills (219) • being introduced to national NHS website or app (168) • being introduced to a local GP online system (88) • getting online information about medical conditions, including mental health (62) • volunteering or becoming a digital health champion (46) • getting online information about wellbeing activities (25) • getting online information about local health service, pharmacy, dentist (13) • getting online information about healthy activities (10) • other (66)	Based on records from 20 of the 22 hubs, collected over 6 months: • 7 in 10 attendances spent time accessing some kind of health information • 6 in 10 attendances included finding information about a wellbeing activity • 6 in 10 attendances included digital skills training and development • 5 in 10 attendances included finding information about local support • 4 in 10 attendances arrived via local social prescribing

Different types of digital health hub

Digital health hubs varied in where they were based, who they reached, how they were led and supported, and what they provided. This reflected the diversity of local places, existing partnership infrastructure and wherever the vision, energy and capacity for supporting digital health existed.

The table sets out three typical settings, derived from evaluating a sample of 12 digital health hubs. Overall, digital health hubs based in GP practices provided a more limited offer (helping patients learn how to use their GP online services or the NHS Website). Digital health hubs based out of libraries and community organisations tended to focus on how people can build digital confidence to benefit their wider wellbeing and community engagement, as well as for digital health transactions.

Table 2: Three typical settings for digital health hubs

GP Surgery (local health setting)	Community organisation (civil society setting)	Library (civic building setting)
Where: Support is likely to be provided from a consulting room (training, advice) and in the waiting room (awareness-raising). Creating space for a digital health hub is a challenge. Where efforts have been made to develop peer support, this is mainly linked to existing arrangements, such as a Patient Participation Group.	**Where:** Support is likely to be provided throughout the building. Creating space for one-to-one support can be a challenge but community organisations are successfully embedding digital support in existing drop-in sessions. The work is intensive, and benefits from a dedicated worker as well as trained volunteer peer support.	**Where:** Support is likely to be provided throughout the library, with an emphasis on making staff aware of the health and wellbeing potential of digital. Outreach and taking the digital health hub 'on tour' to local libraries works well as an additional or alternative way to engage people.
What: GP surgeries have a practical need to introduce their patients to the online systems they use. They recognise the benefits to patients (and their practice) of wider wellbeing support, but energy and capacity to engage with this varies.	**What:** Community organisations are interested in wellbeing and usually start by wanting to understand the whole person, their interests and concerns, and work with them to identify appropriate support. They are often the first to know when local online health systems aren't working.	**What:** Some (not all) libraries already support internet use and have the skills and resources to integrate this with digital health. Some libraries are connected to county or borough wellbeing initiatives, which offers potential for digital health inclusion.
How: Typical activities for a digital health hub based in a GP surgery: • support with finding health information online • being introduced to the NHS website and NHS App • being introduced to GP online systems, including booking appointments or ordering repeat prescriptions online	**How:** Typical activities for a digital health hub based in a community organisation: • support with finding health information online • being introduced to the NHS website and NHS App • being introduced to GP online systems, including booking appointments or ordering repeat prescriptions • gaining digital confidence • support with finding local wellbeing information • support with finding enjoyable things online that can provide a distraction from anxiety, trauma • reaching and engaging people who might not feel comfortable in other settings (GPs, libraries) • facilitating community groups	**How:** Typical activities for a digital health hub in a library: • support with finding health information online • gaining digital confidence • being introduced to the NHS website and NHS App • being introduced to GP online systems • support with finding enjoyable things to do online • support with finding local wellbeing information

Defining a digital health hub

A digital health hub...

Supports people's health and wellbeing overall, as well as digital health literacy

Supports people to find reliable health information online, and be aware of fake information; helps people to feel confident about registering and using online NHS, GP and health services; also helps people use the internet to find out about local support and community groups. For some people (e.g. refugees, asylum seekers, people with complex lives), this is also about helping them access health and dental care in ways that feel safe; and responding to what matters most to them (which may not be their health; building trust can open this up in time).

Builds trust and starts with what interests people

Takes a person-centred holistic approach: 'whatever is important to you is important to us'; not providing digital health help if that is not what matters most at that time; introduced digital in ways that respond to their interests before moving onto health or wider wellbeing; responds to immediate needs, such as booking a GP appointment if that is what matters.

Goes where people are

Makes people feel welcome and comfortable because the digital health hub is based in places where people already go and meet, and have trusted relationships.

Reduces social isolation and improves community connectedness

Shows them ways to keep in touch with friends and family digitally; opens up conversations to support wider wellbeing and community participation.

Builds bridges between health, care, and community sectors

Finds new ways to work together, refer or signpost, use social prescribing. For GP-led digital health hubs, this involves becoming more community focused. For community sector-led hubs, this involves relationships with local health systems.

Leadership and location of digital health hubs varied. What emerged as essential was for any digital health hub to identify and mitigate the risks associated with who they are and the role they play in local health.

For digital health hubs led by GP surgeries, this likely involved building a stronger awareness of local community organisations, signposting, using social prescribing appropriately, and commissioning an active community sector partner to collaborate.

For digital health hubs led by community or voluntary sector organisations or libraries, this likely involved partnerships with the Clinical Commissioning Group, GP practices and (where in place) social prescribing link workers.

Enablers

"We use things people are interested in like cooking, catching up with things you've missed on TV and then you go from Coronation Street to say mindfulness on YouTube. The learning for us is about how to combine health with their hook. It's learning by stealth."
Staff

The evaluation identified a range of 'enablers' of change. Where these were present they made a great difference to what the digital health hub was able to achieve.

• **Atmosphere and approach**
A friendly and welcoming atmosphere, with support provided by 'people like me'; taking time to build relationships and trust; introducing digital health in ways which are active, natural and not medical; helping people overcome their fear of technology.

• **Digital devices and connectivity**
Using technology people already have, trust and feel comfortable using; providing good free WiFi and funding for tablets and dongles; and providing devices people can use for social or side-by-side learning, or privately.

• **Staff and volunteers who are ready to explore digital health together**
Training and supporting digital health champions - staff, volunteers or peers who can introduce people to digital inclusion for their health and wellbeing.

• **Going where people are and starting with their interests**
Taking the digital health hub out into other local spaces and places people meet; tapping into what matters to people; and actively building this into GP processes such as birthday appointments or special clinics.

• **Engagement from local GPs and primary care staff**
Active GP practice engagement, especially where the hub was led by a community organisation; and enthusiasm of the practice manager and reception staff (this applied also to digital health hubs which were led by CCGs and GP practices).

"What draws them in is down to encouragement from the practice manager – she really encourages them and promotes it. We had a meeting with her and she sent out the info to all of the practice's networks."
Staff

"[We] want to create a relaxed drop-in service, not strict times, just say we're here to answer your questions. Mainly it would be about health but would help them with tech too."
Staff

"People are interested in their diet, in a specific health issue which could be diabetes, cancer, it could be anything… but at the same time they don't want to be misinformed."
Staff

Barriers

Alongside these enablers, the evaluation identified barriers to change. Not all were experienced by all the digital health hubs, and some showed signs of being resolved as local partnerships developed. Some of these barriers reflect the wider barriers that community and voluntary sector organisations can face when engaging with local health systems (Baird et al 2018; Bull et al 2014). These include: complexity of the health system; attitudes of some clinicians towards community organisations; commissioning frameworks; resource constraints; and challenges for community organisations in capturing data on health impacts (NPC 2014).

> *"They keep saying they will pass the referrals to the social prescribers. I tried to give my card to social prescribers who come to our office for meetings, so they can refer people"*
> Staff

> *"We never anticipated that GPs would jump at the chance, but we have been slowly chipping away. We'll get there... the penny of social prescribing is dropping."*
> Staff

- **Limited local NHS and GP engagement**
  Some digital health hubs led by GPs struggled to provide more holistic digital health support, beyond helping a patient to use their own GP online system. (This might reflect prioritisation of what the practice needs, perhaps to meet targets). Where digital health hubs were not led by a GP surgery, it could be difficult to get support or referrals. In many areas, social prescribing was not yet very advanced.

- **Diversity of online GP services and systems**
  When several different GP online services and systems are in use in the same locality, this adds an extra challenge for community-based digital health hubs.

- **Time and resource**
  It takes time to build trust and help people overcome their fear of technology; and to build local partnerships where these are not already in place. Short-term 'pathfinder' funding deterred some local GPs from engaging.

- **Depth and diversity of local community needs**
  Understanding and meeting a wide variety of local needs is challenging. Even where organisations already reach a particular community or client group – refugees and asylum seekers, homeless people – they still found they had new things to learn about how to engage people with health and digital.

Future potential for digital health hubs

"We see the potential of the project growing as more people begin to benefit from digital health options and online opportunities for wellbeing and we will be continuing to help, deliver and grow our digital health offer, along with other digital learning, as best we can."
Staff

Digital health hubs are an approach which can be adapted elsewhere to improve digital health literacy and prevent digital exclusion from widening health inequalities or reducing access to health services.

Building on lessons from both phases of the Widening Digital Participation programme, one approach to scaling would be to build a national network of local digital health hubs that are each:

• embedded in their community

• responsive to what matters most to people

• delivered by paid staff, volunteers and peers

• realised through local partnerships which build on community assets and collaboration

• focused on supporting local people's health and wellbeing in general, as well as encouraging them to use NHS and GP services online, and benefit from digitally-enabled health services.

A coordinated national strategy for digital health hubs in communities would include how to:

• Spread the concept and communicate the value of digital health hubs as a way of improving digital health literacy, especially in deprived areas and for disadvantaged groups

• Encourage investment through Integrated Care Systems or Sustainable Transformation Partnerships and Clinical Commissioning Groups so that community sector partners are supported and resourced to deliver digital health hubs as part of health systems

• Develop a proportionate framework for measuring progress towards outcomes

• Develop appropriate regional and local commissioning frameworks for digital health hubs to address health inequalities - recognising the time it takes to build partnerships

• Establish a nationally-networked community of practice for digital health hubs, to share learning and co-create ways to improve digital health literacy and community engagement.

Digital health hubs are an approach which can be adapted elsewhere to improve digital health literacy and prevent digital exclusion

Chapter 3

Digital health and people with complex lives

People who face severe and multiple disadvantages (homelessness, substance misuse, mental ill health) are more likely to experience poor health outcomes and barriers to health services. Poverty, violence and racism can compound these disadvantages. Barriers to health are also affected by status (being a refugee or seeking asylum), low English language ability, and low digital access and skills. Working with people to discover what matters most to them, several pathfinders explored ways to mitigate some of the barriers to accessing health and care services, and tap into opportunities to use digital for better health.

Trust

Trust is always important in health, even more so where people face severe and multiple disadvantages and barriers to accessing services. Some may also have had negative experiences of services and therefore be more likely to self-exclude. Lack of trust - in systems, services and also in technology - was a recurring theme among pathfinders supporting those with complex lives, facing multiple barriers and severe disadvantages.

Equally, trust, and the time to build relationships, featured highly as an ingredient for success in supporting people with complex lives. Pathfinder partners had already built up trust with individuals. This meant they were well positioned to support them to access health services. They could act as an intermediary, helping to rebuild relationships with health services. They could mitigate barriers to accessing online health services. These barriers included digital barriers (low digital skills, lack of digital access, low trust in technology); language barriers (where people had low or limited English language skills and pathfinder partners had staff or volunteers who could speak minority languages); as well as barriers such as no address or the need for in person ID verification. As with many of the digital health hubs, trusted relationships helped to widen conversations about health and wellbeing.

Linked to trust was the importance of 'going where people go'. As with the most successful hubs, these pathfinders were based in places that people already trusted. Places people felt welcome and comfortable; where the starting point was whatever mattered to them.

Other ingredients for success were:

• Going where people go - finding and engaging people where they feel comfortable

• Starting with what matters to people and what interests them

• Taking a whole person approach

• Support provided by 'people like me' (diversity, inclusion, peer support, in my language)

• Local cross-sector and multi-agency coordination.

Three pathfinders illustrate well the potential of digital health inclusion as a route to supporting people who experience deep social and economic exclusion.

Supporting people who are homeless

Life expectancy among homeless people is far lower than the national average. Premature deaths can occur because of treatable medical problems. This makes improving access to healthcare for homeless people a priority.

Health providers can fail to meet the needs of people experiencing homelessness. People who are homeless may also self-exclude from services. Use of online health services by homeless people can help. However, digital exclusion is high and complex among homeless communities. Some people have good digital skills but lack a device, cannot afford data, or access public WiFi (e.g. not feeling or being welcome). Some people do not trust technology. Some have low digital skills and low literacy.

Seaview provides services for complex lives in Hastings. Through the Widening Digital Participation programme, Seaview aimed to improve access to healthcare among people who were homeless or insecurely housed.

Seaview - homelessness and mental health

Seaview aimed to support homeless and insecurely housed people to access health information and support. They tested (1) using tablets to triage health concerns of rough sleepers; (2) helping clients who visit the wellbeing centre and other public spaces to access online health information. During the pathfinder:

- 122 people received in-depth support from Seaview and partners
- 31 Digital Champions were recruited, including peers
- Over 3,000 web pages were viewed by participants; 30% related to physical health conditions and 15% related to mental health conditions.

Conversations started which led to better access to healthcare and steps to self-manage health. This can rebuild trust with health services; but this trust is fragile and can be easily lost. One rough sleeper talked about her depression. By accessing NHS information online she found out her GP should review her medication regularly, but "I don't think she is and I don't like to ask. My mood is very low sleeping rough. There are also lots of different antidepressants which I was not aware of." She booked to see her GP, who reviewed her prescription and also referred her for physiotherapy.

Seaview outreach workers used smartphones to improve health advice for rough sleepers. They took photos of injuries or symptoms and shared them with St John's Ambulance, which provided a clinical opinion. Initially, outreach workers felt digital health was added pressure. This changed when they saw benefits to clients (addressing unmet health needs) and themselves (removing pressure to make clinical decisions).

Seaview staff were already talking about health with clients. The tablets provided by the pathfinder meant these conversations were improved through jointly accessing health information online. This helped Seaview advocate for clients with health services, and helped clients manage their health.

Seaview and partners also improved the local digital health infrastructure. Partners included St John's Ambulance, the Clinical Commissioning Group, library service, council, voluntary action, Citizens Advice and a local recovery alliance. Together, they provided:

- Access to devices in trusted locations, with selected links to online health information

- A community of support using volunteer digital champions - including peers - to support service users to access health information online

- Dedicated 1-1 sessions in Seaview's wellbeing centre and the library, with trained staff

- Improved membership offer of the library for people with no fixed address, and who needed longer than 30 minutes to use the computers.

Supporting people with substance misuse

Building on insights from Seaview in Hastings, two further pathfinders were supported which worked with people who face greater barriers to good health and accessing health services. These were 999 Club in Lewisham and Addaction in Wigan and Leigh (since rebranded as We Are With You).

Understanding that people respond on the basis of what is most important to them at that moment means that individual journeys are seldom linear. Trust, patience and a caring environment created conditions for conversations about health. Through the pathfinder, it emerged that digital technologies and digital inclusion can enhance these conversations and lead to activation in people's health.

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

We Are With You is part of a national drug, alcohol and mental health charity. They partnered with local GPs, hospitals and pharmacists, the police, probation service and a homeless shelter. Digital access outside of their service is a challenge. Many clients feel uncomfortable in the local community centre or library.

Initially, digital health support was provided on a one-to-one basis. It was then rolled out to an existing group session - the Breakfast Club - to open up access to transient and homeless clients. We Are With You kept things simple: constantly offering access but never insisting; and focusing on the NHS website to avoid inaccurate information.

> *"We want to avoid Dr Google"*
> Staff

We Are With You helped people get online, find health information and where to get help out-of-hours. Between August and December 2019, staff recorded 34 clients using the digital health project (some more than once). This included getting information about a health condition (16); about a local GP, pharmacy or dentist (13); and about healthy activities (10).

The multiple layered health issues of the client group means they are often concerned about immediate needs rather than wider health and wellbeing. Through the pathfinder, We Are With You succeeded in widening the conversation to public health or lifestyle issues. They also enabled clients to find out about health conditions, which they might not want to discuss with staff.

Six steps to digital health conversations

1. Identify a community space which offers 'whole person' support, and is already trusted by people with complex lives or from the community.

2. Work with CCG, GPs and others to make referral and registration journeys easier.

3. Find someone to lead - a Digital Health Champion. This can start with one person and evolve to be part of everyone's roles. This person is not a health expert or a digital expert. Their role is to show what's possible in using digital for health, and start conversations.

4. Buy some tablets. Make sure the WiFi is good. Designate space for private conversations.

5. Install links on devices to trusted sites like the NHS website and Learn My Way.

6. Use tools like One You Quiz to start conversations on health while introducing digital. Even bits that don't seem relevant can open up important conversations.

7. Follow what matters to the individual.

Supporting people seeking asylum and refugees

Asha is a charity in Stoke which supports asylum seekers and refugees (through skills development, food, advice and social activities). Destitution, social isolation, anxiety, poor health, post-traumatic stress and language barriers are experienced by many of their service users. Locally, Asha has referral relationships with a refugee health project, GP practice and mental health hospital, and is developing social prescribing links.

> *"I started Learn My Way a few months ago and still look at it … More confident to access health services"*
> Service user

Asha provides free digital access daily and supports digital skills using the free online learning platform, Learn My Way. Asha adapted the digital health hub approach: (1) a Digital Health Peer Support worker ran group and one-to-one sessions; (2) Asha trained refugees and asylum seekers as digital health champions. As well as registering with GP services and finding health information online, people have learned how to use WhatsApp and Facebook groups to reduce social isolation.

Between April and December 2019, 236 people used Asha's digital health hub. Their priorities (some multiple responses) were: using the NHS website and app (113); digital skills support (106); and becoming a digital health champion (42). One service user talked about now being in a position to deal with other health issues, such as giving up smoking, having had support for immediate issues.

> *"I didn't know how to use a computer and he showed me the basics … I tried to reach some information about how to manage my stress … Sometimes so stressed I didn't want to buy food myself … It was not easy before but even now I try to stop smoking cigarette, alcohol, everything … I feel more confident now"*
> Service user

Asha's understanding of asylum processes, all-welcome attitude, holistic provision, and strong use of peers as digital champions allowed Asha's digital health hub to support people who experience severe disadvantages and other barriers to healthcare. This included English language barriers, which were reduced through having staff and volunteers who spoke different community languages, and offering English language and conversation classes as part of Asha's wider offer.

Limitations of a digital-first health system

Asha, We Are With You, Seaview and other pathfinders identified solutions, but they also revealed some of the limitations.

A recurring example was opening a patient account to access GP online services. This usually requires an address, a photographic ID and in-person verification of ID. Each of these is a barrier for people with complex lives, limited English language and/or people who lack trust in services. Some organisations used their centre address as a proxy address and provided a vouching letter. But requirements to appear in person at the GP surgery made people much less likely to register. Inclusive service design can (and should) reduce this barrier; but some of the issues (especially lack of trust) have deeper roots in people's experiences of services and in wider systems. For some of the most disadvantaged individuals, experiences like homelessness, seeking asylum, not being able to speak English, and lack of trust in service providers or in digital technology itself - all of these can make even well-designed digital health services inaccessible.

Digital transformation of health services can exclude people who already face barriers to accessing healthcare and support - unless there is deliberate, sustained support to reduce or remove those barriers; and unless digitalisation is seen as part of a service or solution; not as the whole solution. Physical and digital services should come together. Any patient or service user should be able to use the journey or pathway that works for them - whether that is digital, physical, or a mixture.

For example, a pathfinder in Dorset aimed to support pregnant women from socially excluded groups, linking this to the introduction of a new online service: Maternity Matters. Support was provided to women and partners for whom registering their pregnancy online was a barrier – through local organisations and a helpline. Alice - pregnant and homeless - was supported to register in a local library by a worker at the homeless shelter. Sara and Mohammed - who had no internet access and low English language – called the Superfast Dorset helpline, who registered them over the phone and referred them to a local Digital Champion.

"We developed this way of completing forms (mediated access) as a number of women we spoke to had a medical need to get the form done, and we were concerned that any delay in them seeing a DC [Digital Champion] might cause stress. Equally we have spoken to women, whose first language isn't English, who wanted to see a DC [Digital Champion], as that was an easier way for them, than explaining complex medical matters over the 'phone."
Staff

Finally, several pathfinders found that poor quality WiFi was a barrier, even where other conditions were in place to support digital health inclusion for excluded groups. For example, a GP surgery in a rural area had built trust with a local traveller community, and was keen to host digital health sessions. But these sessions had to be cancelled due to the poor WiFi in the GP surgery.

Chapter 4

Disability, dementia and digital health inclusion

Digital and assistive technologies can transform lives, enabling adults of all ages to live more independently. Organisations like the Molly Watt Trust and Ability Net advocate for equal access to the digital world through accessible design and assistive technology. Yet people with impairments, disabilities or long-term conditions are much more likely to be digitally excluded (Lloyds 2020).

Pathfinders tested different ways of influencing GP practices, residential care settings, and local services to support people and carers to benefit from digital. Two pathfinders explored how to build the skills and confidence of carers (informal older carers in Leeds; paid carers in Newcastle) to use digital to support them in their caring roles. One pathfinder (West Yorkshire) reversed the challenge and explored how GP practices can change to improve the patient experience of visiting the GP, where patients already use digital and assistive technologies.

GP practices supporting people with sensory impairments

All organisations that provide NHS care or publicly-funded adult social care are legally required to follow the Accessible Information Standard. Yet many people still receive information in formats they are unable to understand, and may not receive the support they need to communicate. Assistive technologies people use in their daily lives aren't always accepted for use with their GPs. Sometimes this reflects data security concerns; and sometimes this reflects lack of interest or awareness. This can stifle finding low-cost solutions which would improve accessibility and patient experience. For example, a visually impaired patient may want to get medical letters by email instead of post, so they can use an app to read out the contents in private, instead of asking a neighbour to read them out.

A pathfinder led by mHabitat built on a review by the West Yorkshire and Harrogate Health and Care partnership into barriers faced by people with visual and hearing impairments. This identified issues including: booking appointments, accessing buildings, consultations, and staff awareness. The team reviewed assistive technology to improve interactions between health providers and people with sensory impairments. Two approaches were then used in parallel.

- Digital champions in community organisations were trained to support people with sensory impairments, allowing them to find out what that would suit them.

- Experts with lived experience advised GPs on accessibility - identifying physical changes or changes in working practice. This included being more open to accepting assistive technologies that work for patients in their everyday lives.

Co-designed with people with sensory impairments, this pathfinder succeeded in finding low-cost and even free solutions (e.g. changing accessibility features on a phone). Small changes could improve the whole patient journey and experience.

> *"I don't feel so anxious about going to the doctors now that I know I won't have to explain that I can't see well and that I need help."*
> Patient; her GP put a flag on her record

Improving outcomes for people with learning disabilities in residential settings

People with learning disabilities in residential settings sometimes lack agency and choice. Digital can unlock new activities, interests and expand horizons. Many people with learning disabilities miss out on these experiences. This may reflect access and affordability, or concerns from family and care providers about safety (Bricknell 2018). The pathfinder led by Community Integrated Care in Newcastle tested how to address this in residential settings. It responded to two drivers: improving efficiency through digital systems; and improving quality of life of residents.

"A massive drive to running this pathfinder was to support staff to help residents...we are still scratching the surface, building confidence of staff and services"
Staff

One care setting installed WiFi, provided staff with tablets, training and ongoing support. Others bought an advocacy app and digital communication aids. Overall, six residents and 44 care staff were supported. Care staff weren't expected to be 'digital experts'. The ethos was about taking a 'let's find out together' approach. Where staff saw the benefits for residents, this increased their own motivation and confidence. This suggests that - even where an intervention is focused on upskilling the workforce - there is value in addressing digital inclusion of service users alongside.

Case study:
Sandra's story

"Sandra's world has opened up. We are going to different places and doing different things all the time".
Joyce (care worker)

Joyce and Sandra have used a free piano app to improve dexterity; used Google Street View to check holiday destinations are wheelchair-friendly; and cast YouTube videos on TV.

Case study:
Helen's story

Helen likes Billy Joel. She has been helped to look up Billy Joel on YouTube as his music calms her. She is now reading up on Newcastle docklands, where her dad worked. She is keen to learn more and find places and activities she can go to - using her self-directed support budget in more varied ways.

Supporting carers of people living with dementia

Around 850,000 people in the UK live with dementia. Many are supported by friends and family members (Alzheimer's Society 2018). Carers often struggle to manage their own health and wellbeing (Carers UK 2019). Digital participation can offer 24/7 access to information and advice, provide practical support, social connections, help with relaxation, entertainment and pursuing interests. Yet digital exclusion remains a significant issue among carers and people with long-term conditions.

In Leeds, the Leeds Library Service led a pathfinder on dementia, collaborating with local organisations and carers groups. This was integrated with the 100% Digital Leeds programme, Leeds Health and Wellbeing Strategy, and Leeds Health and Care Plan Outcomes. A coordinator, hosted in the 100% Digital Leeds team, was funded through the Leeds Integrated Better Care Fund. The coordinator provided training and resources to help community organisations integrate digital inclusion into support they already offered, such as dementia memory cafés.

Over 12 months, nearly 800 people were engaged. This included 81 carers and 91 staff and volunteers who trained as Digital Champions; 69 carers who trialled iPads or Alexa in carers' groups or their homes. A closed Facebook group was set up for carers, and a list of dementia-friendly and age-friendly apps was created.
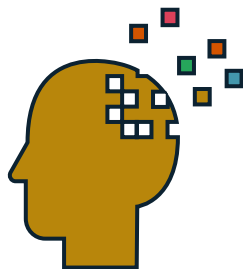
"I've learned all sorts! I'm nearly 81 years old, and we always used public telephones. I never thought I could do this"
Family carer

Carers using digital for the first time or with limited skills reported many benefits:

- Practical support with their caring role (online health information, medication reminders)

- Improved wellbeing - relaxation, reminiscence, fun

- Improved social connections - online peer support, connected to community support

- More confidence, including digital confidence.

"Finding something like this iPad to give me enjoyment in the everyday, giving myself some 'me time' and to use it to have more lovely moments... it's given us both a bit of our old life back"
Family carer

"I can ask [Alexa] for advice around health symptoms and I know it's NHS approved information"
Family carer

Carers who tested Alexa found it useful for setting reminders (about medication, appointments, exercise) and for accessing NHS health information online. They felt reassured as the advice was provided through a trusted NHS source. Social and wellbeing benefits were particularly valued.

Around
**850,000
people**
in the UK live with
dementia

Case study:
Diane and John's story

Diane is a full-time carer for her dad, John, who has been living with dementia for seven years. He has physical health issues and low communication skills. Before introducing an Alexa device into their home, Diane had over 20 reminders and alarms on her phone related to her caring role.

Diane couldn't initially see how Alexa would benefit their lives. She gave it a go after hearing another carer's good experiences. Since installing Alexa, Diane has programmed daily medication, exercise and appointment reminders so Alexa reminds John to do these. She made prompt cards so John can use Alexa independently if he wishes to.

"I can't tell you how great it is. Using these reminders and features of Alexa has been life-changing. I don't feel like a broken record anymore. I can talk to my Dad and chat about other things other than just asking him to do these tasks all day, when I speak to him he can be chatting about a memory or we can laugh about something on the TV... He has now become so much happier, it makes me so emotional to think how much it's changed his life and mine... I can't imagine our lives without it".

Supporting people living with dementia to use digital was not the focus of the pathfinder. Further work is needed here, for example building on work by DEEP (UK network of dementia voices) on 'Dementia Diaries'. In the Leeds pathfinder, a few people with dementia engaged with 'Alexa' independently. Most were unable or had no interest in doing so. Concern about financial safety was raised by some carers.

The pathfinder gave family carers the opportunity to try out digital with support, and without the stress or costs usually incurred. As part of a digital health inclusion strategy, this has been invaluable. There is strong local support for sustaining the work.

"Using the digital technology has made the sessions more interactive, the carers and their loved ones are socialising more, there's more energy and buzz in the room and they all seem so much happier. We can't imagine our sessions without using the digital now" Staff

A number of practical recommendations emerge from the Leeds Dementia Pathfinder:

- Include people with dementia and carers in local strategies for digital health inclusion
- Co-design with carers to understand what support might benefit them
- Find and engage existing carers groups and services for carers and people with dementia
- Integrate digital health inclusion into carers' groups and memory cafés
- Provide digital champion training to carers, as well as staff and volunteers
- Support online peer support for carers, alongside local face-to-face groups.

Supporting carers to benefit from digital

- Bring digital devices into carers groups and memory cafés
- Keep sessions fun; try different apps and devices (e.g. Alexa)
- Support carers to be Digital Champions
- Follow people's interests and go at their pace
- Address accessibility (settings, voice activation, accessible apps)
- Use WhatsApp groups to share tips and support
- Help carers to use digital as a joint activity

The pathfinder
gave family carers
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Chapter 5

Older people, social care and digital inclusion

The population of people over 65 is growing in the UK. There are almost 12 million people aged 65 and over in the UK, with 3.2 million aged 80 and over, and 1.6 million aged 85 and over. Later life brings reductions in independence and with many developing chronic health conditions (CfAB 2019). There are many ways to increase quality of life in older age. Digital technology is one of these. It can benefit older people with long-term conditions or who are going through life transitions (such as bereavement or increased caring responsibilities) by opening up access to online health and care support, enabling people to get more out of life, keep in touch with others, and make life easier.

Internet use is still lowest among the oldest age groups. People over seventy are more likely to be 'offline' (never online or not recently online), even more if they have low incomes, disabilities or health conditions (Ofcom 2020, Richardson 2019). Despite this, there is currently no national provision in England to support older people's digital inclusion and digital health literacy. This is now urgent. The International Longevity Centre highlights that COVID-19 risks widening health, social and economic inequalities caused by digital exclusion, and should catalyse acceleration of digital inclusion efforts (ILC 2020).

Integrating digital inclusion in social care

In Sunderland and Thanet, two pathfinders tested ways to address this through small system changes in social care, and through supported housing schemes. Older people were also among the groups accessing digital health support in many of the digital health hubs.

The pathfinder led by Age UK Sunderland provided free digital skills classes to older people in deprived areas, in community venues and sometimes in people's homes. The value of this offer was picked up by Sunderland City Council's Community Therapy Service. Social care teams recognised the opportunity to build support for digital skills at a transition point: when older people are first referred to their service - the start of their social care journey. This is a time when there can be motive to learn, as digital technologies can help people maintain independence and reduce isolation.

Through the pathfinder, 71 older people with care and support needs received in-depth support to improve their digital skills, confidence and motivation.

While simple and scalable, this relies on relationships and resources. Since the pathfinder ended, this has been a challenge. The referral route from social care teams is no longer explicit. More positively, the relationship between Sunderland City Council and Age UK Sunderland has continued through Age UK's Front Door Service.

Embedding digital inclusion into local health and social care pathways is not easy. Evidence on health and care integration identifies funding and workforce challenges as barriers to systems change; where integration has been successful, local relationships and shared purpose have been pivotal (HoC 2018). This is evident in the Sunderland pathfinder. Partners recognised the benefits of digital skills for independent living, recovery and health. They tested ways to link social care and digital inclusion provision. In so doing, social care services made better use of community assets. Establishing a clear referral route also enabled social care staff to be more confident in introducing older people to how digital technology might help them get more out of later life.

> *"It's about the first point of contact, when they're just starting to experience issues that affect their independence, and helping them to help themselves to stay connected to their community, to start plugging in to internet resources that are out there, and to everything Age UK have in their digital offer."*
> Staff

In Thanet, Orbit Housing Association designed a community-based project to build the digital skills of disabled older people living in supported accommodation. Key elements were to engage people where they are, and to provide digital inclusion learning which responds to people's personal interests. A peer-led model was used. Orbit Housing co-ordinated and trained older people to be digital champions or peer mentors. The peer mentors supported other older people to build digital skills and confidence, and try things out so they could find what worked best for them (for accessibility and dexterity).

Through the Thanet pathfinder, 84 older people with care and support needs received in-depth support to improve their digital skills, confidence and motivation. Nineteen older people were peer mentors.

In Thanet, as in the Leeds dementia pathfinder, Nailsea pathfinder and other digital health hubs, older people wanted to test out new things. They valued peer recommendations relevant to their lives and they also valued the social aspect of digital health inclusion sessions. Since the pathfinder ended, the peer-led group has continued to meet and grow, led by a peer mentor. The group has reached into the wider community, secured a community investment grant, and joined the network of community partners run by Good Things Foundation.

The following recommendations build on learning from the Thanet and Sunderland pathfinders.

- Embed digital inclusion into care pathways by including questions about digital (access, use, confidence) during initial assessment of social care and support needs

- Establish effective referral routes to local providers of digital inclusion, as a way to embed digital inclusion into local health, social care and housing partnerships

- Life events can be a motive to use digital, as long as people feel the benefits quickly

- Social aspects of digital inclusion sessions are valued and help reduce loneliness

- Arrange outreach classes in community settings, or do home visits, to reduce travel barriers

- Train and support older people as peer mentors to support digital health inclusion

- Support people to learn to stay safe online, and find what works best for them (including for accessibility)

- Remove barriers to digital health inclusion created by housing, health and care providers: provide reliable, free internet access; design digital services to be accessible by everyone.

Case study:
Margaret's story

Margaret is 86 years old and joined the digital inclusion sessions at Age UK because she needed support to use her laptop. It was purchased by her son on her behalf. She had it for a year, but had not used it. The Age UK Digital Inclusion Officer resolved a few technical issues – slow internet speeds and updates. After a few sessions, Margaret was introduced to a volunteer Digital Champion, Janet. Janet is 72 years old and has volunteered with Age UK for 10 years. The pairing with Margaret was successful and, after a few breaks due to illness, Margaret was able to use her laptop independently. She reads the local newspaper online, and keeps in touch with her son via email. She learnt to do online shopping, and learnt about online safety and scams, as well as how to use the NHS website.

"Modules on Learn My Way helped build my confidence to use the internet on my own and health websites were very useful. I used NHS.uk to look up my medication as I was concerned about some side effects of one of my new medications"
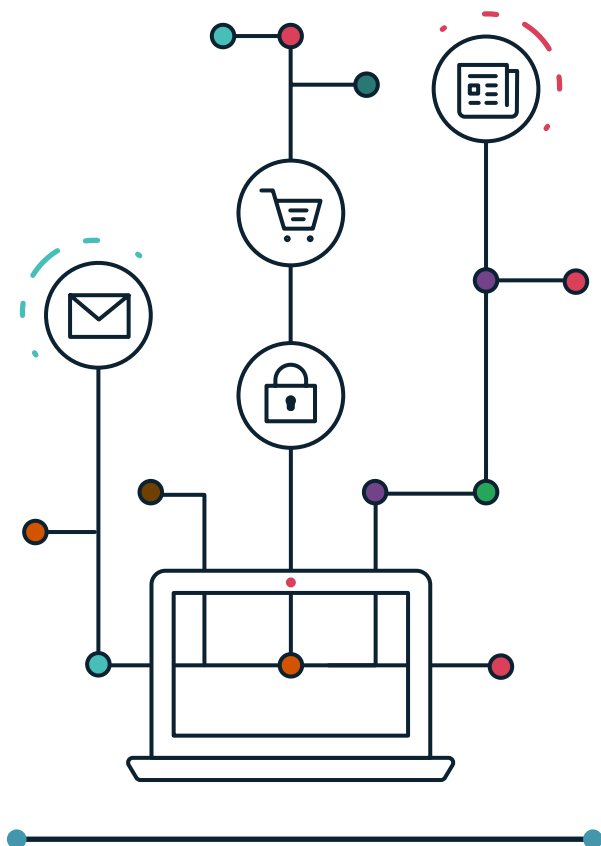
Chapter 6

Co-designing digital health services

When decision-makers and technology experts are themselves digitally-enabled, there is a risk that digital health services, products and tools are designed without recognising the needs of people with low digital health literacy. The ubiquity of smartphones can give false assurances of the levels of internet access and digital inclusion.

Importantly, as several of the pathfinders discovered, co-designing for accessibility and inclusion can mean using what is already familiar and everyday. It is about finding the best solution with people; not necessarily about making something new. It is also about testing assumptions about why something solves a need for that person. Co-design of health care services - bringing patients and staff together to improve care pathways and provision - is not new (Robert et al 2015), but it feels even more important at a time of rapid change in digitally-enabled health care services.

Digital health services for young adults

"I feel like organisations or the NHS need to keep up to date with their socials. That's where we are, and they need our attention so we don't end up with illness that could have been stopped"
Young person

When it comes to young people, there is a risk of assuming all young people are digitally included. Work by the Carnegie UK Trust has identified young people who experience digital exclusion as an overlooked group (Wilson & Grant 2017). Even if young people have digital literacy, they may lack health literacy. Some young people feel GPs do not listen fully or always believe them, and may be more likely to attend A&E than visit their GP (NHS England 2018). In Tower Hamlets, young people involved in the pathfinder described being even less likely to go to their GP for support around mental health compared to physical health (Tower Hamlets Healthwatch 2020).

"When I see stuff like WebMd and it tells me I have diabetes or cancer I get a little scared and don't want to go to GP cos what if it's true"
Young person

Young people identify social media as a help and a hindrance to mental health. What they want from mental health support is a combination of local support (drop-ins, appointments), moderated online support (for immediacy and anonymity), and peer support - online or face-to-face (Healthwatch 2020).

In Islington, the Clinical Commissioning Group engaged 17 young people through workshops to understand young people's requirements for mental health services. Following this, they involved young people in reviewing NHS-approved digital resources for mental health to help select suitable resources. The pathfinder helped commissioners to think differently about their digital strategy. Young people's recommendations were taken on board by the Sustainable Transformation Partnership, including commissioning online counselling services for young people.

"We have very clearly heard what young people want in terms of health information and it's not leaflets. They want something digital that they dip in and out of."
Staff

In Tower Hamlets, an area with one of the highest rates of child poverty, Tower Hamlets Healthwatch had already been engaging young people to understand what mattered to them. Building on this, the pathfinder supported 143 Young Influencers to test how to use digital to get local young people engaged in their health. Most of the young people were from the local Bangladeshi community.

The Young Influencers wanted an online channel of communication about health that they could trust. They tested an app, BetterPoints, which was geo-localised and tailored so young people could get rewards for health activities. This included physical activities and health engagement (e.g. health surveys). 448 young people engaged through BetterPoints or other digital tools. The Young Influencers shared their findings with the local alliance of local health and social care providers and also helped the Mental Health Support Team to improve mental health engagement in local schools.

Many of the insights from young people's involvement in pathfinders are relevant across all ages.

Designing digital health services for young people

- Involve young people in user testing throughout developing any digital health tool or service
- Digital first is not digital only; young people value face-to-face support and peer support too
- Design for lower literacy; using smartphones a lot doesn't mean you have good digital skills
- Paying for data and personal access can be major barriers for young people
- Young people value learning from peers who have been through similar situations
- Address concerns about bullying, false information, and confidentiality
- Use rewards, games, humour, simple language, GIFs and clips
- Complicated signing up processes can quickly put young people off
- Apps are easier to install on phones; website URLs can be hard to remember
- Digital health tools need to be easy to find in online places where young people are
- Geo-localised apps strengthen links to local support, but rarely have a big following; young people are less likely to find or install these apps without additional outreach.

Using Facebook to support cancer screening

"It's about public messages and how to take a different approach. Your traditional approach from a health professional would be, we'll create a profile of the service, and we'll just send out messages. What they're doing differently is saying 'Why don't we go out to where people are on the internet, and infiltrate their space a bit more?"
Health professional, Stoke

In Stoke-on-Trent, the North Midlands breast screening service set out to address the declining trend in attendance of breast screening appointments, especially women attending for the first time. It had significant success in reversing the declining trend through using social media to engage with women, as well as promote services. First-time attendance increased by an average of 12.9% between screening cycles in 2014 and 2018 across all seven sites. The minimum increase at a single site was 9% and the maximum was 26%.

Facebook was chosen because it is already, and increasingly, used by women in the target cohort; and can be used by people with limited digital skills. It is easy to tailor messages and send direct messages as well as open communications. Traditional mass mailings cannot address all the questions women may have, so women are directed elsewhere. This requires time, effort and health literacy. For women at risk of non-attendance, this is a hurdle which may result in disengaging.

"If I had not seen the post on Facebook I would not of asked or checked myself... you only go doctors if you're ill... and to be honest I don't want to use the doctor's appointment system on me just asking questions I would feel I am using valuable appointment time"
Service user

Importantly, this pathfinder is a reminder about the power and application of co-design for more inclusive digital health services. Co-design is about finding the best solution with people - and not necessarily about making something new. Harnessing the benefits of an everyday digital platform - a familiar online space where women already met - in turn enabled the power of community: women using the platform to encourage other women to attend breast screening.

The approach is being replicated elsewhere. Around 350 General Practice nurses and other staff have been trained as Digital Health Champions, including to use social media to engage with patients, as well as to promote services. Already, North Preston Medical Centre has seen a 25% increase in women attending for cervical screening after a Facebook campaign (NHS Digital 28 October 2019). A recent evaluation of the Northern Staffordshire Technology Enabled Care Services programme confirmed that social media supports engagement with harder to reach groups and those with historically lower engagement, especially when using tools like Facebook which are familiar for patients, carers and clinicians (RCGP 2020).

Around

350 General Practice nurses

and other staff have been trained as

Digital Health Champions

Using Facebook to boost breast screening

In Stoke-on-Trent, there had been a 10 year decline in screening attendance for first-timers. Using social media increased attendance across all seven sites. The minimum increase at a single site was 9% and the maximum was 26%. The North Midlands breast screening service used Facebook to:

- promote the screening service using paid ads and peer-to-peer promotion
- reach women who may have had negative healthcare experiences, through engaging them in special interest groups (e.g. trans women, women from BAME communities)
- address known concerns (e.g. is it painful, will any men be present)
- show women what screening involves, using videos to show the room and introduce staff
- provide reassurance through testimonials from women who have used the service
- arrange appointments through Facebook messenger.

Using Facebook to support people with long-term conditions

Having a long-term condition can feel isolating. What people often need is information - or even just reassurance - that is relevant and at the time when they need it.

The Stoke-on-Trent pathfinder explored the use of closed groups on Facebook as an additional support service for people with long-term conditions. It set up groups for atrial fibrillation, multiple sclerosis, and cardiac rehabilitation. Each was moderated by nurse specialists. These provided access to peer support, helped people newly diagnosed to adjust, and helped people with chronic conditions to understand fluctuations. Online and face-to-face support came together where people were close enough to meet.

"If you can imagine, if you're sat there with that condition, and none of your family members have it, and your heart rate is going all over the place, it's quite a lonely place to be and I go on to the [Facebook] group to find that support"
Service user

"The MS [Facebook] group was really active [in the summer] because the heat as having an impact on people's MS. Now, you could've got a new MS patient who doesn't know why they feel really ill, because they don't know the impact of the heat, so the nursing staff were quick to put information on, preventative information around the heat."
Staff

For clinicians, the closed Facebook groups provided a direct route to disseminate timely information. Nurses moderated the groups to ensure peer support did not stray into medical advice. They spent around 1 hour each week moderating and posting content. As groups became established, this reduced to around thirty minutes. The lead nurse for the atrial fibrillation group estimated that 25% of queries resolved through the Facebook group would otherwise have led to a GP visit.

In Nottingham, a pathfinder led by Connected Nottinghamshire worked in partnership with Macmillan and the CARE (Cancer and Rehabilitation Exercise) programme - which had already created a closed Facebook group as a "safe place to share stories and information." Members could post about themselves, exercise information and achievements, and provide encouragement through peer support, photos and humour. CARE programme service users co-designed and championed the group.

> *"One of the most important things the CARE Facebook group has done for me is helped me build a tight social network of like-minded 'CanLivers' who meet, communicate, share concerns, troubles, successes, advice and overall promote mental wellbeing"*
> Service user

Low-tech solutions

In Portsmouth, a pathfinder led by Portsmouth Hospitals Trust set out to test how digital technology could reduce low blood sugar level episodes in care homes. The plan was to test digital monitoring kits and instant messaging apps with carers and the community diabetes team. However, it emerged that the main demand was for easy-to-access pictorial resources. So a low-tech solution was produced: a PDF document with a simple pictorial record of treatment choices and step-by-step list of actions. Staff in community teams found it more convenient to have a PDF on their laptop, and used the links for further information. Staff in nursing homes have asked if this might be developed into a simple app which they can install on their phones.

This pathfinder - similarly to pathfinders which used Facebook or supported carers to test 'Alexa' - reminds that low-tech solutions and everyday digital platforms can provide effective solutions.

Chapter 7

Upskilling the health and care workforce

Research estimates that 13.6 million workers in the UK have essential digital skills for life, but lack the essential digital skills needed for work (Lloyds 2020). Nowhere is this more important than in the health and care sectors. Within the NHS, Health Education England is leading action through the 'Building a Digital Ready Workforce' programme. This aims to build the digital literacy and capabilities of everyone working in health and social care (HEE 2018). Interest in supporting digital ambassadors and digital champions is fast growing (RCGP 2020).

Upskilling the health and care workforce brings benefits in enabling staff to deliver more effective and efficient care. More training is moving online; being able to use online learning is essential. Health and care staff can also encourage patients and service users to use digital as a tool to improve their health and wellbeing. To do this, health and care workers and managers will need support to build their own digital skills and confidence, and their own digital health literacy.

Digital champions in health and care settings

As part of the NHS Widening Digital Participation programme, several pathfinders explored ways to upskill local practitioners in health, care, and community services. Sometimes this was a focus from the outset but sometimes, the need for upskilling practitioners only became apparent as pathfinders faced reluctance or resistance from staff to use digital tools.

For staff, barriers included:

• Lack of time (real or perceived)

• Lack of digital confidence, knowledge and skills - including low digital health literacy, and worries about not being an 'expert'

• Worries about implications for their roles, job security, and service quality

• Lack of permission or 'situational support' to use digital at work (e.g. limited managerial support, lack of equipment, poor Wi-Fi, unable to work remotely).

At an organisational level, barriers included:

• Lack of equipment, poor connectivity and poor coverage

• Concerns about risks associated with digital and data security

• Concerns around the regular need to upskill staff if turnover is high

• Culture in specific settings, where staff are not given permission to use digital (e.g. to support time management, or help service users or patients to get online)

• Lack of resources, partnerships, or assets to offer support through digital transformation.

In Lancashire and Cumbria, Redmoor Health led a pathfinder to provide digital skills training to health and social care professionals, alongside individual and organisational level support. Around 140 staff across eight care homes attended sessions (managers, matrons, activity coordinators, health workers, care assistants and cleaning staff). In Newcastle, Community Integrated Care led a pathfinder which provided digital skills training to managers and workers in residential care settings. Forty-four staff members and six residents were helped to develop digital skills and confidence.

Additionally, a Digital Health Champions Training pathfinder was supported to explore the role of hyperlocal digital inclusion partners in training health and care workers to be digital health champions. This pathfinder was delivered by three community organisations in the network supported by Good Things Foundation. These were Zest (Sheffield), DBC Training (Derby) and Starting Point (Stockport). Each centre ran a series of one-off sessions, with a view to Digital Health Champions assisting their colleagues to use digital health resources, and then assisting patients or service users.

All three community organisations had existing health and/or social care contacts, but the pathfinder provided an opportunity to test how such relationships could be built around a training offer. Workshops helped staff examine their own attitudes to digital, identify the barriers (faced by staff and patients or service users), and take practical steps to overcome these. Sessions were attended by 98 staff between November 2019 and February 2020, including nurses, health practitioners, health trainers, health and wellbeing coordinators, social prescribers, weight management practitioners, and business support staff. These sessions were not intended to build basic digital skills, which was a gap for some staff with low skills.

Across all these pathfinders, there were positive results with many staff recognising the roles they are well-placed to play as digital health champions, so they can provide better support to patients or service users, and to colleagues.

Upskilling practitioners to use digital health

- Identify and support staff who have low digital skills
- Go to where people are if possible (e.g. on site in a care home)
- Support practitioners to become digital health champions in their service or locality
- Recognise digital champion roles as part of professional development (e.g. certificates)
- Reassure that champions aren't expected to be experts; exploring together is what matters
- Set up a local network of digital health champions for peer support
- Use formal training alongside ongoing, light-touch support

These positive results tell a similar story to evaluation findings of the Technology Enabled Care Services programme. This aimed to upskill General Practice Nurses to have improved digital skills. Through the digital champion training, confidence of GPNs significantly improved. At the start, only 10% of GPNs estimated that they used digital technology more than half of the time in practice. By the end, this increased to 50% of GPNs using digital technology more than half of the time; and 97% felt confident in helping colleagues and sharing their knowledge and expertise (RCGP 2020).

A number of recommendations arise from the pathfinders for in-house or external training providers.

- **Ensure buy-in from employers**
  Organisational level buy-in is necessary for culture change. Give staff permission to develop their digital confidence, and use the digital skills they may already have. Enlist local NHS organisations and GPs to encourage staff to sign up in community digital champion sessions.

- **Ensure line managers are on board**
  Promoting the benefits of digital to managers and supervisors is key to a digitally-confident culture. Explore ways to link digital to professional development; incorporate learning about new digital health apps as part of staff meetings; provide a vision and strategy for staff.

- **Initial exploration to understand specific needs**
  Spend time to understand specific needs and organisational cultures, and gather data and perspectives. Visit staff where they work and involve them in co-designing support. Support professional development through formal training and certificates.

- **Identify and support staff who lack essential digital skills**
  Where staff lack digital confidence themselves, then a one-off digital champion training session is less suited. Some staff will need tailored, ongoing support and access to learning around basic digital skills - so they can build their own confidence first.

- **Make it tailored, convenient, flexible and social**
  Design interventions to fit the work environment. Visit to find out what staff use; understand strategic priorities; train champions 'on site' and ideally in groups - with 'on tap' support after.

- **Involve service users as well as staff**
  Even where the focus of an intervention is on the health or social care workforce, there is value in addressing the digital inclusion of patients and service users alongside.

Supporting service users and staff together

Supporting residents to use digital was viewed as a long-term ambition in some of the care homes, once care staff felt more comfortable and confident getting online.

> *"A massive drive to running this pathfinder was to support staff to help residents… we are still scratching the surface, building confidence of staff and services."*
> Staff

One care home trained staff to use ORCHA - a digital system which rates different health apps and makes it easier to find the right app for a specific condition. Staff downloaded NHS-approved apps on long-term conditions so they could better support residents. In another care home, staff were supported to use a digital watch (Fitbit) as an indicator of blood pressure for those residents who become agitated when a more traditional measure is used.

As familiarity with digital increased, more staff felt able to support residents to use digital themselves. This helped some staff develop their own digital confidence. In the Redmoor Health pathfinder, care home staff talked about how the training encouraged them to support residents to benefit from different digital tools, including VR headsets, Fitbits, iPads, Alexa and Skype. Some staff felt residents had been given 'a new lease of life'.

> *"When it comes to technology I'm willing to give anything a go. Every experience is good. As you get older it's important to try new things."*
> Service user

"We have a number of end-of-life patients and if they want to go on a rollercoaster or walk on the beach one last time the VR headsets can recreate that."
Staff

"It's just been the 75th anniversary of the Holocaust and a 94-year-old resident mentioned it so we were able to download a virtual tour of Anne Frank's house."
Staff

In one care home, Amazon Alexa has become part of everyday life.

"The Alexa has made a big difference. Residents will ask for a 'bit of Elvis' when they're having their dinner. We encourage them to interact with Alexa and ask questions. They'll ask about the weather or what time it is. I asked one resident what she wanted for dinner and she replied 'I'll ask Alexa'."

As staff learned more about technology, they found other ways to offer support, such as a Facebook page to update residents' families. Staff also gave examples of where increased digital confidence had improved their own lives, such as learning how to use online shopping. Staff with low digital skills were positive about the free online digital skills courses on Learn My Way.

"The [Learn My Way] website has links to help people budget, we shared that with staff… then some of the staff came back to say this was useful, and that they used it for residents, but also for themselves."
Staff

Digital health champions in community settings

In Nottingham, Connected Nottinghamshire worked with Self Help UK – Beyond Diagnosis Service, which provides emotional support to people in Nottingham and Nottinghamshire affected by cancer, delivered by a team of specially trained volunteers. Training was provided to volunteers to become Digital Champions, giving them the tools (tablets and data packages) they needed to support people.

"being able to improve our large network of volunteers IT skills was an excellent opportunity"
Staff

Volunteers were recruited who were passionate about championing digital services through emails and face to face contact. Some had limited digital skills but were motivated to improve their own knowledge so they could provide better support to others. Six of the eleven volunteers were deaf, in order to address a known gap in support for deaf or hard of hearing people with cancer.

Using digital inclusion to reduce isolation as a means to improve health and wellbeing was at the heart of the pathfinder's approach. Volunteers met service users in their homes or cafés or wherever they felt comfortable. An important part of the Digital Champion training was about using digital to keep in contact through different online peer support groups and video calling tools.

Many digital health hubs and pathfinders used the concept of digital health champions as part of their delivery. For Asha, a community organisation which provides holistic support for refugees and asylum seekers, training a small number of digital health champions from different communities, who shared cultural backgrounds and languages, was identified as a practical way to offer and sustain support.

"Get the digital champions to spread the word. Focusing on training a few people very well … Because we are dealing with different cultures, people with different cultural backgrounds, language problems and so on."
Staff, digital health hub

Training volunteer digital champions

Don't:

- Just send in a 'Digital Champion'. This didn't work for us. People need trusted, familiar faces who offer the right thing at the right time.

- Treat 'digital' as something separate. All we are doing is increasing the toolkit of people who support those with a long-term condition every day.

- Think everyone is going to be comfortable being called a 'Digital Champion'. Use whatever term feels appropriate.

- Try and make digital the solution to all problems. This is about helping people get information that they need and adjust to changes in their life.

Do:

- The best people to be digital champions are those who know something personal about the individual - their partner's name, if they have a pet, or support a football team. They already have a relationship and trust.

- Reassure everyone: they don't have to have all of the answers or be 'digital experts'. Exploring together is key.

- Train volunteers or champions in groups to share ideas and for peer support.

- Train in places and at times when people feel most comfortable.

- Identify people's digital skills and confidence levels - don't assume everyone is in the same place.

"...if they want to go on a rollercoaster or walk on the beach one last time the VR headsets can recreate that." Staff

Chapter 8

Conclusion and recommendations

This report has summarised learning from across 23 locally-led pathfinders - each with a different focus ranging from refugee health to supporting informal carers of people living with dementia - as well as from pathfinders which further tested and evolved a model of community 'digital health hubs'. Pathfinders engaged a wide range of stakeholders and delivery partners, including: Clinical Commissioning Groups, GPs, hospitals, local authorities, care homes, housing associations, specialist voluntary sector providers, libraries, community organisations, patient participation groups, carers groups and (most importantly) the people who are affected by services themselves.

Practical pointers and recommendations have been shared along the way. There is also a wealth of information on Good Things Foundation's Digital Health Lab website - including 'How To' Guides, lessons learned and pathfinder evaluation reports. In this final section, eight overarching messages and recommendations from across the programme are pulled together.

1. Recognise digital access & skills as a social determinant of health

Being able to afford internet access and having the digital skills to use the internet safely are now essential in many areas of life: education, employment, income, social participation, and access to information and services. All of these are among the wider or social determinants of health. Poverty, unemployment, low educational attainment and disability: all correlate with digital exclusion (Ofcom 2020). They also all correlate with lower healthy life expectancy (Tinson 2020). COVID-19 has further exposed the digital divide, and intersectionalities between ethnicity, poverty, poor health and racial discrimination (Bibby & Leavey 2020, BMJ 2020).

Recommendations:

- Recognise digital access, skills and confidence as a social determinant of health.

- Improve national data on the links between digital inclusion, health care and outcomes.

2. Co-design digital health services

Co-design is a method of involving patients or the public, practitioners and decision-makers in designing services. It is about finding the best solution with people; not necessarily making something new. For example, using Facebook in the Stoke-on-Trent pathfinder reversed a declining trend and led to an average rise of 12.9% in first time breast screening attendance. Co-design - whether with young people from the Bangladeshi community in Tower Hamlets or homeless people in Hastings - reminds that digital is part of a service or solution; not the whole. Digital services can amplify existing barriers to accessing health care, unless action is taken to reduce these. Alongside deeper barriers such as poverty, lack of skills, and lack of trust in health services and technology - other challenges were digital identity and in-person verification, literacy and English language barriers, and lack of reliable, secure, free connectivity in health or care settings.

Recommendations:

- Patients should be able to use what works for them - whether digital, physical, or a blend.

- Co-design with patients should be at the heart of a digitally-enabled NHS; it should always include co-design with those who have low digital skills and face barriers to health care.

3. Improve digital health literacy in the population

Strategies to improve health literacy have been identified as important for reducing health inequalities. This makes population digital health literacy a priority, alongside low literacy and English language barriers. The internet and social media also carry health and wellbeing risks. Through the programme, we have helped to surface the essential digital skills for health. One area for further research is how to support people with low digital skills to understand how their health data is used. Building digital health literacy brings clear benefits. 83% of people who used Learn My Way health courses said they felt more confident about using online tools to manage their health (Good Things 2019/20).

Recommendations:

- Improve population digital health literacy, and support safe and healthy internet use.

- Improve people's understanding of how their health and personal data is used.

Strategies to improve health literacy have been identified as important for

reducing health inequalities

4. Develop 'digital health hubs' to improve inclusion

Community 'digital health hubs' emerged as a practical way to build digital health literacy and improve access to health and wellbeing support. A digital health hub is trusted and embedded in the community; welcoming and friendly; responds to people's interests and needs; reaches people who are currently poorly served; builds digital and health literacy together; is delivered with the community sector; and supports wider wellbeing, as well as access to digitally-enabled health care. Peers and volunteers – 'people like me' – take time to build trust, with a mindset of 'exploring together' and 'whatever interests you interests us'. With the right partners and promotion in place, digital health hubs build stronger bridges between the community sector and health systems.

Recommendations:

• Further test and scale digital health hubs – a community infrastructure for inclusion.

• Develop commissioning frameworks which support the role of community sector partners.

• Establish a national community of practice for digital health hubs.

5. Build trust and relationships with poorly-served groups

Trust, and the time to build relationships, featured highly as an ingredient for success, especially in supporting people with severe and multiple disadvantages. Where delivery partners had already built up trust with people, they were well positioned to support them to access health services - online or locally. People facing multiple disadvantages may also have had negative experiences of services, and therefore be more likely to self-exclude. Trusted people could help to rebuild the relationship with health services, and mitigate the barriers to accessing online health services. Whether in digital health hubs, housing schemes, or general practices - being supported by 'people like me' and 'in my language', and 'exploring together' helped to build digital health literacy and confidence.

Recommendations:

• When commissioning for digital health inclusion, recognise the time needed to build trust.

• Train and support peers to be digital champions for health and care.

6. Harness the benefits of digital for health and wellbeing

Across the pathfinders, the benefits of digital inclusion for health came to the fore time and again. In Leeds, when family carers of people living with dementia had the opportunity to test iPads and Alexa devices in their home, and community carers groups introduced devices into their regular sessions, this brought practical, emotional, social and wellbeing benefits. In care homes, widening digital participation benefited staff and residents. Across older people, people dealing with homelessness, substance abuse or seeking asylum, digital inclusion opened up conversations about health and wider wellbeing. Some with low trust in services felt able to use the internet to access reliable information. Others found that accessibility settings and assistive technologies could make all the difference.

Recommendations:

- Support people to try out different devices and assistive technologies.

- Include information about how to improve accessibility when training digital champions.

7. Improve digital skills in the health and care workforce

A lesson across pathfinders was not to make assumptions about the level of digital skills, confidence and motivation among the workforce. Reluctance from staff to use digital tools also reflected concerns about service quality and job security, as well as organisational and practical issues. Providing support to staff delivered positive results. Many staff recognised the valuable roles they could play as digital champions, so they can provide better support to patients and colleagues, without having to be a 'digital expert'. Added value emerged where strategies to build digital skills and confidence included both staff and services users together (for example in residential care settings).

Recommendations:

- Build digital confidence and motivation of staff, following Health Education England's lead.

- Train, support and build a network of digital health champions in a service or locality.

8. Embed digital inclusion in strategies and partnerships

Successful partnerships improved the local health, wellbeing and digital inclusion infrastructure. In Hastings, the pathfinder led by Seaview (a homelessness project) included St John's Ambulance, the CCG, council, library, Citizens Advice and a local recovery alliance. Together, they improved access to devices in trusted locations, adding selected links to online health information, and created a community of support using peer and volunteer digital champions. In Leeds, the dementia pathfinder was integrated into the 100% Digital Leeds programme, Leeds Health and Wellbeing Strategy, and Leeds Health and Care Plan Outcomes from the start to support sustainability and coordination. Integrating digital inclusion into existing support, such as dementia memory cafés, was a core focus.

Recommendations:

- Embed digital inclusion and digital health literacy in local health and wellbeing strategies.

- Build on community assets and collaboration across health, care and community sectors.

...the benefits
of digital inclusion
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and again.

Annex 1: List of Resources and Pathfinders in the Widening Digital Participation programme

Information about the Phase 2 Pathfinders - including How To guides, tools and templates, and evaluation reports - is available on the Good Things Foundation website: <u>Digital Health Lab</u>.

Widening Digital Participation - How To Guides

<u>How to co-design digital inclusion in health</u> (2020)

<u>Digital health hubs in community assets</u> (2020)

<u>How digital can help people with complex needs (homeless communities and those struggling with substance misuse)</u> (2020)

<u>Dementia - a how to guide for digital inclusion in health</u> (2020)

<u>Using digital in supporting people with cancer</u> (2020)

<u>Digital ready health professionals</u> (2019)

<u>Digital inclusion for older, isolated people</u> (2019)

<u>Digital inclusion for older people in housing schemes</u> (2019)

<u>Digital inclusion for people with learning disabilities</u> (2019)

<u>Socially prescribing digital skills</u> (2018)

<u>Using digital with the homeless community to benefit their health</u> (2018)

Pathfinder evaluation reports and lessons learned

Digital Health Hubs: An evaluation for the NHS Widening Digital Participation Programme. (2020) Wendy Sugarman and Leila Baker, WSA Community Consultants.

Supporting Health and Social Care Staff to Embed Digital in the Workplace. (2020) Dr. Sarah Alden.

Dementia and Digital Participation for Health and Wellbeing: Supporting carers and people living with dementia (2020) Dr. Sarah Alden.

Designing Digital Skills Interventions for Older People. (2019)

Digital Health Hub on the Highstreet Evaluation (2018) (Nailsea)

Socially Prescribing Digital Skills Evaluation (2018) (Sheffield)

Using Digital to Help Young People with their Mental Health Evaluation (2018) (Islington)

Using Digital with the Homeless Community to Benefit their Health Evaluation (2018) (Hastings)

Using Closed Facebook Groups for People with Long Term Conditions Evaluation (2018) (Stoke)

Using Facebook to Improve Attendance at Screening Appointments (2018) (Stoke)

Digital Tools for People with Sensory Impairments (2018) (West Yorkshire)

Health and Digital: An evaluation of the Widening Digital Participation Programme (July 2016)

Tower Hamlets Young Influencers Project (2020) by Healthwatch Tower Hamlets

Lessons learned from Nottingham - supporting people through their cancer journey (2020)

Lessons learned from Dorset - digitally-enabled maternity services

Lessons learned from Portsmouth - diabetes in care homes

Lessons learned from Bradford: emotional health and wellbeing of young people (2018)

List of Pathfinders

Below is a list of the main Pathfinders and lead partners and what they set out to test.

Socially Prescribing Digital Skills in Sheffield

Can introducing digital within social prescribing help people to take more ownership of their health?

Sheffield CCG worked with two local neighbourhoods linking digital inclusion and social prescribing.
Partners: Sheffield CCG, Sloan Medical Centre, Heeley Trust

Young people and mental health in Islington

Can digital technology help young people to access appropriate mental health care?

Islington CCG worked with partners and young people to develop their strategy and understand how to select and introduce digital health resources to support young people's mental health.
Partners: Islington CCG, Islington Council

A Digital Health Hub on the High Street in Nailsea

Can a physical space on the high street help support people to improve their digital health literacy?

Tested making a community space to help Nailsea residents improve their lives and health through engaging with digital and community support.
Partners: Nailsea Town Council, 65 High Street

Homeless and insecurely housed people in Hastings

Can digital help rough sleepers get the health support they need?

Explored how to support the homeless and insecurely housed community to use digital to access health information and support that they currently don't feel able to access.
Partners: Seaview, Hastings and Rother CCG, St John's Ambulance.

Young carers and their wellbeing in Bradford

Can digital improve the wellbeing of young carers?

MYMUP tested an online platform to help support young carers with resilience and mental health.
Partner: MYMUP (Making Your Mind Up)

Sensory impairment in West Yorkshire

Can digital tools improve the experience of people accessing health information and support?

Explored ways that digital inclusion can improve health interactions for those with sensory impairments working with West Yorkshire STP and others.
Partner: mHabitat

Long-term conditions in Stoke-on-Trent

Can social networking improve access to health information for people with long term conditions?

Stoke-on-Trent CCG tested social media for accessing services and Facebook groups for support.
Partners: Stoke-on-Trent CCG, Redmoor Health

Isolated older people in Sunderland

Can digital help to support older people with their move from health to social care?

Age UK Sunderland explored how to engage isolated residents around digital for health and wellbeing.
Partners: Age UK Sunderland, Sunderland City Council

Social housing residents in Thanet

Can digital help people in social housing gain better access to health services?

Orbit Housing Association tested how to engage residents to promote digital inclusion for health.
Partners: Thanet CCG, Orbit Housing

Maternity services and digital technology in Dorset

Can digital help expectant and new parents access health information and support they need?

Aimed to help expectant and new parents to access a new digital platform.
Partners: Dorset CCG, Dorset Council

Diabetes among older people in Portsmouth

Can digital help reduce low blood sugar level episodes in care homes?

Explored how to use digital to identify, treat and prevent hypoglycaemia in care settings.
Partners: Portsmouth Hospitals NHS Trust, Portsmouth CCG

Digital inclusion for nurses

Can digital inclusion enable nurses to tackle problems and improve the care that they give?

Explored how to build digital confidence of nurses and others to improve care.
Partner: Redmoor Health

Digital health inclusion with young people in Tower Hamlets

How can digital engage young people from BAME communities to improve their health?

Worked with Young Influencers to identify how digital can support young people's health.
Partner: Healthwatch Tower Hamlets

Improving cancer support using digital in Nottinghamshire

How can digital help those with a cancer diagnosis feel supported and access information?

Explored how digital can improve the services and support for people through their cancer journey.
Partner: Connected Nottinghamshire

Digital tools for carers and people with dementia in Leeds

Can digital help carers of people living with dementia on a day-to-day basis?

Explored ways to support local organisations, carers and people with dementia to engage with digital to improve their lives.
Partner: Leeds City Council

Digital inclusion for people with learning disabilities

How can digital technologies improve experiences and wellbeing in residential care settings?

Supported staff in using digital to support their roles and to improve quality of life of residents.
Partner: Community Integrated Care

Digital inclusion and A&E in Blackpool

Can digital inclusion reduce the strain on A&E?

Explored how digital inclusion can help people access other information and support that is more appropriate than A&E.

Partner: Empowerment

Digital Health Hubs - 5 Pathfinders

Building on three early pathfinders (Nailsea, Sheffield, Hastings), five pathfinders further tested and evolved a model of 'digital health hubs' to improve digital health literacy and inclusion.

Partners: Asha North Staffordshire, Destinations, Saltburn, The Wembley Practice,(North West London CCGs), Gautby Road, Blackburn Central Library

Digital Health Hubs - Mini-pathfinders

Further testing of the model of 'digital health hubs' was done by different types of organisations across different locations, each funded for six months.

Partners: Addaction (We Are With You), Cambridge Online at Hester Adrian Centre, Eden Rural Foyer, Computers Within Reach, Norfolk & Norwich Millennium Library, Starting Point, Learn For Life Enterprise, Superhighways, Lincs Training, One World Foundation Africa, Hackney Co-operative Developments (HCD), Redbridge Institute-Gearies centre, First Asian Support Trust (FAST) Ltd, Chapeltown & Harehills Area Learning Project, Citizens Advice in North and West Kent, Citizens Advice Halton, Inspirational Training Institute, Cross Gates Good Neighbours, Kirklees Neighbourhood Housing, The Dales, Castle Point & Rochford CCG, Yarm Medical Practice

Digital Health Champions Training Pathfinder

Three community organisations ran sessions to test the value of their role in supporting NHS and social care staff to become Digital Health Champions.

Partners: Zest, DBC Training, Starting Point

A Final Note: In August, we contacted all pathfinders to find out what has happened since their pathfinder ended. All who replied have taken forward activities and learning. For some, activities have become business as usual, or part of another project. Many described improving strategy, training programmes and resources based on what they learned. A few, such as the Stoke-on-Trent pathfinder, have shared their practice to inspire practice improvements nationally. Several organisations described how COVID-19 has impacted. For example, We Are With You had to stop group sessions and drop-ins but continued to promote the NHS website with clients, where clients have home access and digital skills. Across pathfinders which involved Facebook or WhatsApp groups, these online groups have proven an invaluable way to stay connected while normal services and face-face sessions paused. Others have started remote delivery: Empowerment now uses Zoom to run virtual befriending clubs three times a week to engage people who are still new to using digital for health and wellbeing. In Leeds, where provision of devices to carers of people with dementia and carers' groups was an integral part of the pathfinder, this has proven a lifeline through the pandemic - enabling people to stay connected with friends and family, take part in virtual dementia memory café sessions and boost their wellbeing.

Annex 2: Lessons learned from a design approach

If you would like to find out more about the approach, please contact the Good Things Foundation team, with 'NHS Widening Digital Participation' in your email: hello@goodthingsfoundation.org

Pathfinders: rationale for this approach

Pathfinders were co-designed and delivered by local consortia, variously including Clinical Commissioning Groups, GPs, local authorities, care home providers, voluntary sector organisations and community groups. With support from Good Things Foundation's Service Design team, each consortium identified points in health and care systems, products, processes and patient journeys which could be improved through digital technology and community-based interventions. Pathfinders usually ran for 12 months and were funded by a grant from the programme to contribute towards costs incurred. While every Pathfinder was unique, all Pathfinders were supported to go through a series of five steps, and to draw on co-design principles.

Good Things Foundation Co-design Principles

1. **Design with people, not for them:** The premise of co-design is including those who will be affected most by decisions. They are the experts in their lives.

2. **Go where the people are:** Conversations are more honest when people feel comfortable and safe. Spend time where they spend time. Shift the power dynamic: avoid formal buildings.

3. **Relationships not transactions:** Health is an emotive subject. People's relationships with peers, professionals, digital tools and their environment must be taken into account.

4. **Work in the open:** Share your learning. Share your work. Be transparent in your design decisions. Have confidence to tell people why something worked or not. It will help others.

5. **Understand underlying behaviour:** Look beyond immediate causes to understand the many different factors behind behaviours: personal, social, cultural, economic. Be conscious of, and check, the assumptions you make.

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

Lessons learned

Towards the end of the programme, NHS Digital and Good Things Foundation held a 'retrospective' to reflect on what we felt worked, and didn't, from a perspective of programme design and implementation. Our main pointers are summarised in the table below.

Reflections on Pathfinder Programme design and implementation

What worked well

- Using test-and-learn approaches for local solutions to local needs
- Putting co-design principles at the heart of the whole programme
- Providing up-front and on-tap support to Pathfinders from the service design team at Good Things to help with use of co-design
- Refocusing to test potential for scaling 'digital health hubs' following success of early pathfinders (Nailsea, Sheffield and Hastings)
- Prioritising the production of practical and accessible resources
- Open and regular sharing of resources and reports via the digital health lab website
- Acceptance by NHS Digital and Good Things from the outset that not all Pathfinders would succeed; providing short reports of lessons learned
- Commissioning external researchers to evaluate some of the pathfinders
- Bringing Pathfinder leads together to share learning (this didn't happen often, but was valued when it did)
- Frequent contact between NHS Digital and Good Things core teams
- Taking advice from those with lived experience on how to engage people
- Front loading effort into planning and preparing a good engagement strategy.

What didn't work so well

- The diversity of the Pathfinders (different user groups, stakeholders, contexts) made it difficult to create a clear and coherent programme, and develop 'communities of practice'
- A light-touch approach to data collection and reporting reduced pressures on local Pathfinders but made it harder to aggregate programme impacts and benefits
- Pathfinder partners found it difficult to collect both baseline and impact data, even where data approaches were co-designed with them
- Pathfinder set-up (building local relationships, getting started) took longer than expected, leaving less time for delivery and evaluation
- Staff capacity was stretched in the second half with 'main' Pathfinders to service alongside over 20 smaller 'scaling' Pathfinders
- What happened next and whether a Pathfinder was sustained was beyond the programme's scope
- Digital access barriers like poor quality WiFi in GP surgeries and care homes
- Reluctance from some health and care professionals to engage (sometimes reflecting distrust of digital services; or personal lack of skills and confidence).

What we'd try differently in future

- Take a lean but more robust approach to data collection with a clear evaluation framework (Note: this would require taking a more themed approach overall)
- Improve the process of selecting Pathfinders, including a mid-term breakpoint
- Build in a plan (from the start) to test the potential for scaling, and sequence this to avoid servicing too many separate Pathfinder models at the same time
- Build in resources to develop 'communities of practice' to support Pathfinders (including beyond the end of a Pathfinder) - this requires a more themed approach
- Build in time and support around sustainability and exit strategies (this is always going to be challenging for experimental programmes)
- Build more agility into the programme by delivering through smaller organisations who can tailor support and respond more rapidly
- Build in ways to spread knowledge and involvement (given the breadth and complexity) to avoid it being concentrated in a few people
- Involve larger public sector bodies as steering group members/advisers and funders rather than as agile delivery partners.

Learning from what doesn't work so well

From the outset, NHS England and Good Things Foundation were clear that not all pathfinders would succeed in the way they set out, but that all pathfinders would generate value. The principle of learning from what doesn't work, 'failing forward', is at the heart of design thinking. Two examples illustrate this well.

In Bradford, the MYMUP tool didn't succeed in engaging young people without direct support provided by people they could trust. Nonetheless, through the pathfinder, it became clear that the tool had other benefits. Bradford Districts CCG has since commissioned MYMUP to develop a platform which allows data gathered by voluntary and community services to flow into NHS Digital's Mental Health Services Data Set, and will be available to all providers of NHS-funded mental health services in Bradford.

In Blackpool, a pathfinder was set up between Blackpool Empowering Social Support, North West Ambulance Service and Blackpool Teaching Hospitals Foundation Trust. It built on innovation led by a paramedic to reduce pressures on A&E. This identified frequent attenders, and involved paramedics in providing coaching support to meet underlying needs, including loneliness (NHS England 21 May 2018). While this reduced A&E visits, it created new dependencies on paramedics. The main lesson learned was that NHS bodies, particularly those under extreme stresses, do not have the capacity to try new innovations (even if it is funded). Using smaller, more nimble organisations to innovate and provide 'proof of concept' appears a more expedient way to bring change into systems. The pathfinder is now exploring how to use wider community-based and online assets to address the challenge. Since the pandemic started, befriending sessions have moved online, using Zoom to run clubs three times weekly, to engage people with lower digital skills.

Annex 3: Additional References

BMA (2020), COVID-19 Analysing the impacts of coronavirus on doctors. *British Medical Association Survey Results for June 2020*.

Baird, B et al (2018), *Commissioner perspectives on working with the voluntary, community and social enterprise sector*. The King's Fund.

Behavioural Insights Team (2015), *The Behavioural Insights Team, EAST: Four ways to apply behavioural insights*.

Bibby, J & Leavey, C (2020), *Learning from lockdown: how can we build a healthier future post-COVID-19*. The Health Foundation.

Bricknell, J (2018), *Doing digital inclusion with the most excluded: People with learning disabilities*. Good Things Foundation.

Bull, D et al (2014). *Supporting good health: The role of the charity sector*. New Philanthropy Capital.

CfAB (2019), *The State of Ageing in 2019*. Centre for Ageing Better.

DfE (2019), *The Essential Digital Skills Framework Guidance*. Department for Education.

Dimitriadis, S (2020), *Straddling the divide: Digital exclusion during Covid19 and beyond*. International Longevity Centre UK.

GP Patient Survey (2020). *Infographic 2020* and *Analysis Tools*.

Healthwatch England, National Voices and Traverse (2020), *The Doctor Will Zoom You Now Insight Report*.

Health Education England (HEE) (2018), *A Health and Care Digital Capabilities Framework*.

HoC (2018), *Integrated Care: organisations, partnerships and systems*. House of Commons Health and Social Care Committee.

Lloyds (2020), *Lloyds Bank UK Consumer Digital Index 2020*.

Marmot, M; Allen, J et al (2020), *Health Equity in England: The Marmot Review 10 Years on*. Institute of Health Equity and the Health Foundation.

NEF (2008), *Five ways to wellbeing*. New Economics Foundation.

NHS Digital Service Manual - Design Principles.

NHS Digital (28 October 2019), *New social media techniques used to boost cancer screening rates*.

NHS Digital (4 July 2019), *Digital inclusion Guide for health and social care*.

NHS England (2020), *Implementing Phase 3 of the NHS Response to the COVID-19 pandemic*.

NHS England (2018), *Improving access for all: reducing inequalities in access to general practice services*.

NHS England (21 May 2018), *Paramedic's brainwave eases A&E pressures by keeping 'frequent callers' away*.

NICE (2016), *Community engagement: improving health and wellbeing and reducing health inequalities*. National Institute for Health and Care Excellence Guidance.

Ofcom (2020), *Adults Media Use and Attitudes Report 2020* and Technology Tracker.

ONS 2017, *An overview of lifestyles and wider characteristics linked to Healthy Life Expectancy in England: June 2017*. Office for National Statistics (This is the latest release).

Patel, P et al (2020), *Ethnicity and covid-19*. The British Medical Journal. BMJ 2020;369:m2282.

RCGP (2020), *Rapid Review: Digital Champions in Primary Care*.
Royal College of General Practitioners.

RCGP (2019), *Fit for the Future*. Royal College of General Practitioners.

Richardson, J (2018), *I am connected: New approaches to supporting people in later life online*. Good Things Foundation with the Centre for Ageing Better.

Robert, G et al (2015), *Patients and staff as codesigners of healthcare services*, in British Medical Journal. BMJ 2015;350:g7714.

Stone, E et al (2020), *Supporting digital inclusion of adults with low English language skills*. Good Things Foundation with Carnegie UK Trust.

Tinson, A (2020), *Living in poverty was bad for your health before COVID19*. The Health Foundation.

The Health Foundation (2020), *The Health Foundation COVID-19 Survey*.

Acknowledgements

For more information
about the project, contact
Good Things Foundation on:

Good Things
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