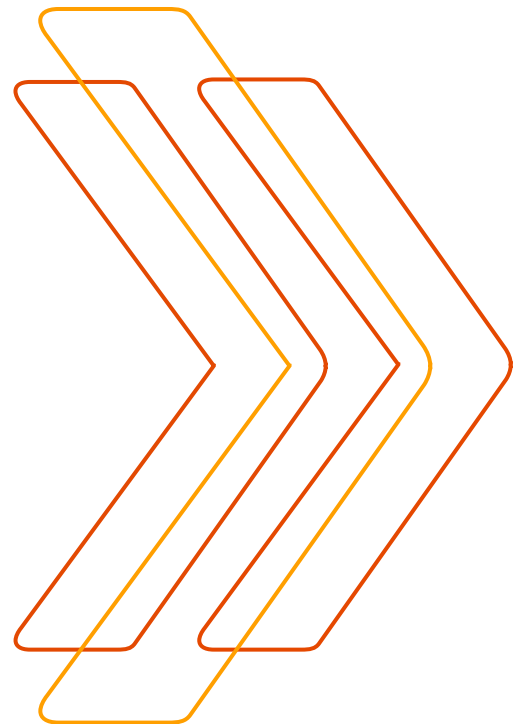The King's Fund>

Ideas that change
health and care

Technology and innovation for long-term health conditions

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This independent report was commissioned by Academic Health Science Network in England. The views in the report are the author's and all conclusions are the author's own.

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1 Key points

- Since Covid-19 hit the UK in early 2020, health care organisations in England have moved services online at a dramatic pace.

- When the crisis is over, health care providers will need to assess the full impact of these changes for staff and service users. A number of questions will need to be answered: for example, was the technology deployed in the most effective way; were downsides addressed; what further changes are needed to achieve full benefits; and how do providers protect the interests of particular groups?

- This paper, commissioned by the Academic Health Science Networks (AHSNs) in England, considers four innovations from the United Kingdom (UK) and the Nordic countries that use digital technology to deliver a step change in treatment.

- While this research was completed before the Covid-19 crisis began, the findings articulate some of the questions services need to answer and the steps they need to follow to implement digital technologies effectively.

- One finding from this and previous research is that technology has often been introduced conservatively in health services, with the aim of delivering small improvements rather than transforming how services are delivered.

- The case studies in our research highlight how digital technology can be harnessed to support more ambitious transformation of care, for example, overcoming some of the limitations of traditional models of care for long-term conditions and delivering more responsive care for people with unpredictable, cyclical conditions. Some of these innovations have allowed services to calibrate treatment more precisely for diseases that affect individuals in different ways.

- During the first months of the Covid-19 pandemic, practitioners have highlighted the potential to bring different services together using digital tools. The case studies in this report also demonstrate the power of technology to stitch together different health and care services, allowing staff across primary care, community services, hospital services and social care to work together to deliver joined-up care.

- Innovative technologies have also enabled teamworking among much broader networks involving family members, peers and local communities, allowing parents to monitor their children's health while at school, or patients to create support communities including peers, volunteers and friends.

- Experiences as a result of the Covid-19 pandemic have highlighted both the challenges and the opportunities of maintaining effective therapeutic relationships through online services. While there is some evidence that poorly designed digital technology can create a barrier between caregivers and patients, our case studies highlight the potential of technology to enable stronger therapeutic relationships, for example, through allowing more regular interaction than typically possible through face-to-face interactions alone.

- Collaborative design involving technology entrepreneurs, health care professionals and patients from the start is an important component of an innovation process. Early collaboration, ideally before problems have been identified or possible solutions developed, enabled our case studies to think as creatively as possible about how to improve care.

- Iterative cycles of improvement to gain feedback from service users and test improvements are also important, particularly given the challenges that particular groups of people face in using digital services.

- The success of digital innovation often depends on what might appear to be small details such as how long it takes for health care staff or patients to log on, how hard it is to rectify a small inputting error, or how long it takes to get through to the call centre if you forget your password.

- For understandable reasons, NHS organisations have not yet been able to incorporate these steps into the adoption of new digital technologies in response to Covid-19. But there are good arguments for completing them if providers retain new online services once the pandemic is over.

- The experiences of our case study sites shows there are ethical and technical challenges around how to transmit, share and use patient data in ways that secure people's consent, maintain trust, protect confidentiality and ensure equitable benefits sharing between different constituencies.

- Our research suggests that the solution lies, in part, in placing patients firmly in control of their own data and how it is used, with simple arrangements for opting in and out of data sharing including the ability to decide who can access the patient's data and for what purposes. In doing so, some of these innovations are helping to empower patients and establish a more balanced relationship between professionals and service users.

- One overriding message from our case studies and other examples is that harnessing technology to deliver transformative change in health care is harder than it might initially appear. The types of innovations most likely to spread are often those that fit within existing structures, making small improvements to existing ways of doing things rather than delivering transformative change.

- If this is the case, there will be a particularly strong imperative to revisit the innovations introduced during the first months of Covid-19 pandemic to ask whether they were ambitious enough. Have services exploited the full

potential of the technology rather than simply addressing the immediate challenges of reducing avoidable face-to-face contact during the pandemic?

- Our case studies suggest that the AHSNs could play an important role in doing so. Each of the examples highlights the role of cross-cutting agencies, whether innovation funds, innovation centres or development agencies, in convening partnerships and structuring ambitious innovation processes.

2 Introduction

It has become received wisdom that the NHS struggles to adopt digital innovation. The Innovation, Health and Wealth report of 2011 highlighted the volume of unnecessary face-to-face NHS appointments (Department of Health 2011). Four years later, the *Accelerated access review* highlighted the obstacle course that innovators face in evidencing and persuading the NHS to adopt digital tools and services (Department of Health 2015). These government reports and a stream of research papers have highlighted the barriers to the spread of digital innovation: top-down and supply-driven approaches; unsupportive leadership and cultures; an absence of appropriate incentives; insufficient funding for innovation and improvement; a lack of improvement capability in trusts; lack of evidence of effectiveness, or lack of understanding of the evidence, amongst many others (Collins 2018; Castle-Clarke *et al* 2017).

Given the extent of these perceived barriers, the pace at which many NHS services have moved online since February 2020 is astonishing. When the scale of the Covid-19 pandemic became clear, many health care providers across England moved, almost overnight, from delivering the majority of services through face-to-face appointments to delivering almost all services remotely. At the end of March, NHS England and NHS Improvement provided NHS trusts with funded access to the Attend Anywhere video consultation platform. Six weeks later, 60 per cent of NHS trusts were using the platform, and the number of online consultations had increased from 200 to 6,000 per day (Rapson 2020).

However, perhaps the most dramatic shift has occurred in primary care. In December 2019, NHS Digital reported that just 15 per cent of 23 million primary care appointments during the month had taken place by phone or online (NHS Digital 2019). By April 2020, 49 per cent of appointments during the month were by phone or online (NHS Digital 2020). Soon afterwards, many GP practices were reporting that they are now delivering more than 90 per cent of their appointments at a distance (Innovation Agency for the North West Coast 2020; Lynch and Wainwright 2020). While it is too soon to assess the full impact, clinicians have highlighted an immediate reduction in waiting times for GP appointments, the ability to make better use of different members of staff, and more time to care for people with complex needs (Boersma 2020).

When the dust settles, we will need to reflect on the lessons from this period on the nature of innovation in the NHS. How much of the established narrative about the enablers and barriers to innovation in the NHS appear credible after

the past few months? For example, are clinicians genuinely averse to adopting innovation if, albeit under extreme circumstances, they were willing and able to make such rapid changes to how they deliver services? Do NHS staff really need financial incentives to adopt innovation, or do they simply need access to resources, such as free access to digital platforms? Which precise changes to working practices in the NHS during the first months of Covid-19 made it possible for staff to make such rapid changes, after so many years when progress was slow?

There will also be a need to review carefully the impact of these innovations for staff and service users. For technology enthusiasts, there is an assumption that technology will transform health care for the better. Very often, this is absolutely the case. Yet there is strong evidence that technology is often introduced conservatively in health care, making small improvements within existing ways of working rather than exploiting its full potential (Christensen *et al* 2017). There is also evidence that careless introduction of new technologies can unwittingly do harm (Obermeyer and Mullainathan 2019; Zitter 2017). Once the UK is through the crisis, there will need to be a careful appraisal of the impact of these technologies introduced at pace, without the usual consultation, governance or evaluation, just as there will be a need to assess the impact of other changes such as to hospital discharge practices (HM Government 2020).

This paper, commissioned by the Academic Health Science Networks (AHSNs), looks at four digital innovations in health services from the UK and the Nordic countries: the TeleCare North programme to provide remote treatment for people with chronic obstructive pulmonary disease (COPD); the Patients Know Best portal and electronic health record; remote diabetes monitoring for children at Helsinki University Hospital; and the Huoleti app for connecting patients with a support network. The case studies were selected following discussions with participants in the UK government's conference on digital health innovation for the Northern Future Forum in 2019.

Each of the examples demonstrates the potential of digital technology to transform care for the better, for example, through establishing more responsive treatment models that better reflect the cyclical nature of many long-term conditions, the diverse patterns of some long-term conditions, and the multiple bio-medical, psychological and social issues they raise for patients. These examples highlight the potential of technology to empower patients, to support stronger therapeutic relationships, to support effective teamworking across professional boundaries and to create networks and communities to support patients. They also show how entrepreneurs and health services can avoid the negative effects that technology has sometimes introduced or exacerbated in health care.

While the case studies were completed before Covid-19 hit the UK, they raise important questions that will be relevant when health services have the time to appraise and refine the digital innovations introduced in 2020. The following sections provide an overview of the case studies and a discussion of key themes regarding effective implementation of digital innovation. The concluding section before the full case studies discusses possible lessons for health services in England as they embed new digital services introduced in 2020. For example, which aspects of the changes should be maintained or reversed, what engagement and evaluation processes are needed, and what further changes are required to fully harness the potential of new digital services?

3 Overview of case studies

TeleCare North

In the late 2000s, a district nurse completing a PhD focused on telehealth at Aalborg University in Denmark highlighted the limitations of traditional health services for people with COPD. Many people would receive their first diagnosis of COPD in the accident and emergency (A&E) department, leading to a stay on a hospital ward, before being discharged back to their GP and nurses in their community health centre. At the time, hospitals struggled to communicate and co-ordinate effectively with community-based services, leading to inadequate monitoring and support after an acute episode. Patients' lives would be consumed with trips to different, disconnected health services, just for simple tests and follow up appointments. Thousands of patients would be back in hospital in a few months' time, with dramatic consequences for their quality of life and significant costs for the health system.

In 2009, researchers at Aalborg University, in partnership with health care staff and technology entrepreneurs, launched their first telecare pilot for COPD sufferers. Health care staff trained patients to use a 'telekit' including a tablet, a blood pressure monitor, a fingertip pulse oximeter and a precision scale. Staff taught them how to collect vital signs using the devices and input the data into the tablet. When patients sent data that was outside expected thresholds, staff followed up by phone or email, advised on self care, prescribed antibiotics or hormone therapy or referred patients quickly to more specialist services to prevent an exacerbation from occurring. At the end of the first randomised controlled trial, 71 per cent of patients reported an increased sense of security, while 61 per cent reported increased control over their condition. Rates of readmission to hospital were 54 per cent lower than for the control group, with average savings of £800 and £1,030 for patients with severe and very severe COPD per year. Telehealth for COPD patients is now being introduced across the whole of Denmark (Witt Udsen *et al* 2017; Henderson *et al* 2014).

Patients Know Best

When Mohammad Al-Ubaydili was diagnosed with a rare immune deficiency in his teens, his family began to keep detailed records to help co-ordinate and improve the safety of his care. Mohammad describes the moment he realised that he and his family were the only true 'experts' on his condition: they were the only ones who had been at every medical consultation. He also describes

how important it was to learn to manage his own care, so he had the independence to travel and study at medical school.

In 2008, Mohammad launched the Patients Know Best portal in the UK. Patients log on to what looks like a medical version of Facebook, with notifications, posts on recent events and icons for test results and care plans. Patients use the system to set up appointments, contact health care staff, see test results and add information about their conditions, including through linked devices such as blood pressure, blood glucose and heart monitors. Patients see their test results in real time, often before their doctors and, like Facebook, they decide who can join their group and access their health records.

Dr Susan Hill, a paediatric gastroenterologist at Great Ormond Street Hospital, described the impact for children with intestinal failure. For the first time, families had a secure way of communicating with her team. For the first time, they could ensure that doctors in an emergency department had accurate information about their child's condition. Sharing information openly created the opportunity for real teamworking between families and services to improve safety and co-ordinate care. With support from the AHSNs in England, Patients Know Best has been adopted in more than 70 NHS trusts in England and can be accessed by more than 5 million NHS patients, making it the most widely adopted patient portal in the UK. Hospitals in Germany, the Netherlands, Republic of Ireland and the United States also use the system, which works in 20 languages.

Remote diabetes monitoring for children

Finland has the highest prevalence of type 1 diabetes in children in the developed world. For parents and children, the impact of the diagnosis can be devastating. Parents need to monitor their children's blood glucose levels day and night, making dozens of medical decisions including on how to administer potentially lethal medication. If a child's blood glucose levels are too high, they can lose consciousness. If their blood glucose levels fall too low, this can cause irreparable tissue damage. At night, it is hard to know whether a child is asleep or in a coma. Children struggle to maintain a normal routine at school, while parents often take sick leave or stop work entirely.

Since the mid-2010s, parents and children in Helsinki have been able to join a Nightscout network, put together by tech-savvy parents who hacked existing sensors so they could transmit data to a server via the internet. Children wear a blood glucose monitor below the skin and an electronic insulin pump, which transmits data on blood glucose levels and insulin doses to a server via the internet for parents to monitor on a smartphone. Consultants at Helsinki

University Hospital have worked with families to improve the effectiveness and safety of care using the network, for example, training parents and teachers to interpret the data and intervene faster, and reviewing monthly downloads of children's data to spot patterns and reduce variation in blood glucose levels.

Families' lives no longer revolve around managing a child's diabetes. Parents can keep tabs on their children's glucose levels during sports practice while they are at work, and they can go to bed knowing that if they need to help their children in the middle of the night, the sensor will wake them up. Meanwhile staff at Helsinki University Hospital have been able to reduce routine follow ups and focus attention on families who need most help managing their children's condition. In autumn 2019, with support from the Finnish innovation agency, Sitra, the hospital established a system for live streaming children's health data to health care staff, so that they can intervene faster in children's care. The next phase is to analyse these large volumes of patient data in the hope that this sheds new light on the condition and how to predict hypoglycaemic events.

Huoleti

In 2016, Carita Savin, a social entrepreneur, secured seed funding from Finnish innovation agencies and others to develop new forms of support for cancer patients. Research suggested that cancer patients received high-quality medical care but very little support between appointments and after treatment. Health care services did not connect patients or their families to peers and people felt as though they were the only ones with the disease. When people are seriously ill, we assume that family and friends will rally round. But research shows that during serious illness, we often get disconnected from our friends and communities (Petitte *et al* 2015). People are awkward when confronting friends with serious illness. They don't know how to manage the first encounter, they back away, and as time passes it becomes more awkward to reconnect.

Carita launched Huoleti in 2017, initially as a service for cancer patients to build support networks. It is now being used in different countries by patients with cancer and is being trialled for people with inflammatory bowel disease and other long-term conditions. Patients and families download the app, invite friends to join their network, and use the app to ask friends, peers with experience of their disease and trained volunteers for support (using a map to find peers and volunteers in their local area).

Rather than contacting people individually, patients tick items on a checklist of issues they would like help with, such as meeting up, going for a walk, help with the groceries or transport to hospital. The app lowers the barrier for patients to ask for help and makes it easier to stay in contact with friends. Helpers come

round with the groceries and stay for coffee and a chat. Patients can contact peers for emotional support or practical help on issues that health care staff may struggle with, say how to make the trip to hospital with the risk of vomiting and incontinence. Spouses can also contact other families with experience of the disease for support.

Data collected so far by Huoleti suggests that patients who use the service are better able to maintain relationships, suffer less loneliness, maintain a greater sense of control over their lives and are more optimistic about the future. There is evidence that patients follow their medical regimes more precisely, experience a greater sense of wellbeing during illness and make a faster recovery.

4 Features of effective digital innovation

Despite their differences, the case studies highlight a set of common features of effective digital innovations in health services. For example, each of these innovations has allowed health care organisations to develop more responsive services that better reflect the nature of many diseases, to enable multi-disciplinary team working, to deliver holistic, relationship-based care and to create and harness communities. The case studies also highlight a number of lessons about effective innovation and diffusion processes, including the need for collaborative design and iterative cycles of improvement. They highlight the role that cross-cutting agencies such as the AHSNs in England, innovation funds and innovation centres in universities, in bringing together partners and structuring ambitious innovation processes.

Responsive services for unpredictable diseases

In its report on *Innovative care for chronic conditions*, the World Health Organization highlights the deficiencies of health systems in treating long-term conditions. Health systems that were built to treat infectious and other acute diseases have established an 'acute care model' for the treatment of long-term conditions, applying brief interventions and rigid treatment protocols to what are inherently unpredictable, cyclical conditions (World Health Organization 2002).

Each of the innovations studied here has enabled services to develop more flexible and personalised treatment processes that better reflect the nature of many long-term conditions. In the TeleCare North programme, district nurses are able to monitor much more closely patients' COPD and intervene proactively with advice or medication, rather than waiting for an acute episode requiring hospitalisation. In Helsinki, health care staff are able to look for unique patterns in data on diabetic children's blood glucose levels and insulin dosages, providing much more tailored and targeted treatment for what is increasingly seen as multiple distinct forms of the disease. Some children are able to maintain the desired blood glucose levels with much lower insulin doses than previously expected, while others need much higher doses than expected. Children also need health care treatment that reflects the specific challenges of their families and daily routines.

Mohammad Al-Ubaydili describes the moment of panic when doctors in a new hospital realise that patients can access all their health records through the Patients Know Best portal, and are looking at test results before the doctors have had time to think about them. Once the panic subsides, Mohammad is often able to engage with clinical teams on how they might adapt their work processes now that they can communicate with patients in new ways, for example, switching from routine 'just-in-case' appointments to 'just-in-time' appointments when patients really need to come to the clinic. One hospital department found that registering 100 patients on Patients Know Best avoided the need for 300 face-to-face appointments, providing patients could receive their test results directly through the portal.

For patients, there appear to be therapeutic benefits in simply knowing that they will be able to contact health care staff easily in the event of an exacerbation, rather than having to battle their way through the system, wait for their scheduled appointment or make use of emergency services. Health care staff reported that, to their surprise, making it easier for patients to contact them reduced the number of contacts and the difficulties managing them. With Patients Know Best, parents can leave a quick message during the night if their child is unwell and know that the nurses will see it when they arrive at work in the morning. Staff can check online that parents had received and opened messages, rather than phoning repeatedly to check that important information had made it through.

Technology-enabled teamworking

A few hours after she had sent her first communications to families through the Patients Know Best portal, paediatric gastroenterologist Dr Susan Hill received a message from a parent pointing out an error. As Susan put it, 'My letters, just like other doctors' letters, often contain errors. But this was the first time in 20 years that anybody had corrected one. I decided that I wanted to send out more letters to families through Patients Know Best and get more help from parents in correcting them!'

Each of these innovations has enabled new forms of teamworking between patients, carers and different teams of health care staff, often leading to substantial changes in who does what, and harnessing a larger team of people's time and resources to improve care. The most obvious changes are in the roles of patients or carers and health care staff. In Helsinki, parents take the main responsibility for monitoring children's blood glucose and insulin doses, with health care staff advising on how they can refine the treatment plan to avoid variation or what to do in a case of a hyperglycaemic event. In TeleCare North, COPD patients take responsibility for a large set of monitoring and data

collection tasks previously carried out by district nurses. Doctors and nurses describe their role as changing to one of a 'health coach' supporting patients with self-management and improving their lifestyles.

Most of the innovations have also triggered substantial changes in how different groups of health care staff work together, in part because they allow different groups of staff to share information and communicate more effectively, and in part because they create opportunities for staff in separate services to use their resources in different ways. With the Patients Know Best portal, patients and health care staff can share information and hold online discussions among a core team including the patient, family members, the GP, community nurses and hospital specialists. In Denmark, the introduction of telehealth for COPD patients, with patients and professionals accessing a shared portal, has also led to closer joint working between GPs, community nurses and hospital consultants. Staff dial into a multidisciplinary video conference to discuss individual patients and their treatment plans, hospital consultants spend more time advising GPs and nurses on how to care for their patients at home, and the number of referrals to hospital has reduced.

Another common feature of these innovations is the profoundly liberating effects of digital home monitoring and supported home-based care. Parents of diabetic children are consumed by the process of manually checking their blood glucose levels and giving insulin injections. Older people's lives revolve around exhausting trips to health services for simple blood pressure tests, their accuracy undermined by the stress and exertion of making it to the facility. Home monitoring and self care allow parents of diabetic children to stay in work and the children to participate in sports and other school activities with their peers, and allow older people to do more than continually shuttle between health appointments.

Relationships enabled by technology

In *The digital doctor*, the clinician Robert Wachter provides examples of how the introduction of technology in health care has damaged the relationship between health care staff and patients (Wachter 2015). He argues that technology reduces the amount of time doctors and nurses can spend listening to and engaging with patients, and directs their attention away from the whole person to medical devices and inputting information into medical records. In mental health and long-term conditions, there is also evidence that the introduction of technology can weaken the therapeutic relationship, preventing doctors engaging with the psychological, social and existential dimensions of illness. In *The digital doctor*, Wachter presents a child's crayon drawing of a visit to her hospital specialist. The drawing shows the child and her family clustered on one

side of the room. The doctor is hunched over his desk at the other side of the room, his back turned to the family, inputting data into the health record (Wachter 2015).

The examples of innovation in this paper demonstrate that rather than inevitably creating a barrier, digital technology can be used to improve the quality of relationships between health care professionals and service users, as well as improving technical aspects of health care delivery. Mohammad Al-Ubaydili argues that Patients Know Best creates opportunities for doctors to develop closer relationships with patients than is possible when relying primarily on face-to-face appointments, where the costs of appointments and scheduling challenges made it hard for patients to see the same doctor or nurse more than a few times a year.

At the University of Leicester School of Medicine, all new medical students learn to provide telehealth for volunteer patients using Patients Know Best over the course of a year. More than 1,500 medical students have been trained so far. When the students meet the patients at the end of the course, there are hugs and tears. The emotional connection between students and patients is unmistakable, and much greater than would be expected if they had engaged through three or four outpatient visits in the year. At TeleCare North, patients have more frequent contact with health care staff than possible in traditional services and, despite less face-to-face time with staff, report a greater sense of security and control over their condition.

Huoleti also provides an example of how technology can be designed to create and sustain caring relationships rather than undermine them. Research during the start-up phase highlighted how surprisingly difficult it is for people to stay connected with friends and communities when they are seriously ill. At the point when it might be assumed that friends rally round, the awkwardness, embarrassment and, in some cases, shame, that accompany severe illness mean that patients may retreat and friends may walk away. Simple design features of the Huoleti app make it much easier for patients, friends and volunteers to connect with each other, for example, allowing patients to contact a group rather than individuals to ask for support or structuring face-to-face contact around helping with practical tasks, rather than awkward visits where discussion focuses entirely on the person's illness.

A possible message from these examples is that innovators and health care staff need to consciously engineer a bias towards relationships into the design and implementation of the new system. For example, health care staff can harness technology to maintain more sustained interaction between a core group of care givers and the patient and their family. Other research from The King's Fund has

highlighted the importance of user-centred design in both developing technologies and redesigning the services that use them (Maguire *et al* 2018).

Shifting the balance of power

As well as enabling more effective relationships, some of these innovations are also designed to shift the balance of power between patients and the professional staff delivering health services. In the UK, any organisation that adopts Patients Know Best gives patients full and immediate access to all information contained in the portal on their health and care. Patients can access test results as soon as they arrive and see everything that has been written about their care. This means that they are in a much better position to alert staff and help correct errors and have detailed discussions with staff about their care. As for relationships above, there is scope to design in features of digital services that support this rebalancing of relationships between service users and professionals, for example, simply ensuring that people have access to their full medical record or ensuring that patients should always be able to decide who accesses their data and how it can be used.

Creating and harnessing communities

These innovations have also supported new forms of teamworking among much broader networks of family members, other carers, peers, volunteers and local communities. In Helsinki, parents with diabetic children can share information on their children's blood sugar levels with teachers. School is a 'critical environment' where children may struggle to control their blood sugar levels or be excluded from activities because staff are worried about managing the disease (Pansier and Schulz 2015).As a result health care staff are increasingly supporting teachers, rather than just parents, in managing children's diabetes.

With Patients Know Best, patients decide who gets access to their health data on the portal, and can choose to give this information to anyone they wish anywhere in the world. While health services have often found it impossible to share health data outside the health system, patients can decide that they want their social worker or peer support worker to have access to data so they can help manage their condition. Huoleti uses technology to connect people with friends, volunteers and peers in a local area, with a map showing their location in the neighbourhood. Like the Buurtzorg model of nursing in the Netherlands, it harnesses the willingness of neighbours and local communities to support people when needed.

Collaborative design

Each of these examples highlights the need for collaborative design between technology entrepreneurs, health care professionals and patients from the start

of an innovation process, before problems had been identified or possible solutions developed, so that they can think as creatively as possible about how to improve care. In Finland the Kertomalla Paranee project, a partnership between innovation agencies, public sector hospitals and private providers, conducted more than 100 interviews with cancer patients to understand the strengths and weaknesses in existing cancer care. Staff at Huoleti then spent two weeks with service users in an intensive design camp to understand how technology could help address unmet needs. Researchers at Aalborg University spent a year running workshops with health care staff and service users before launching their first telecare pilot for COPD patients.

Even though this paper focuses on success stories, interviews suggested that this is still not the most common development path for technology-based innovation in developed health systems. Instead, many argued that an inverse development path was more common: entrepreneurs and health care professionals would develop innovations that reflected narrow perspectives such as an interest in particular technologies or, at best, practical problems faced by health services, rather than starting with a broad inquiry into people's underlying needs and opportunities to serve them differently. Service users were often engaged in the process at a late stage, when problems and solutions had been devised, with the aim of making the intervention more 'user friendly'.

In diabetes care, technology firms working with health services in the United States had developed new digital blood glucose monitors. However, they only enabled the monitors to send data to a pager a few metres away. A group of software engineers with diabetic children, fed up of waiting for a solution to the problem, hacked the Dexcom blood glucose monitor so that they could transmit data to a remote server via the internet, making it possible to monitor their children's blood sugar levels from a distance. While there are significant risks in service users modifying medical devices in this way and it cannot be condoned, this example highlights the value of actively involving service users, families and carers in the design process.

Iterative cycles of improvement

The examples here highlight the importance of iterative cycles to gain feedback from service users and test improvements. Those suffering from long-term conditions are more likely to be older, from disadvantaged socio-economic backgrounds and with lower levels of health and technology literacy. Many may have poor eyesight and reduced fine motor skills. Even in the successful TeleCare North pilot, a large number of patients dropped out of the programme. Evaluations highlighted the difficulties that patients faced remembering their usernames and passwords, remembering how to use their 'telekit' and inputting

data into their tablets. Older people are more likely to have long fingernails and fingers with callouses, making it harder to operate a touchscreen. When they pressed the buttons repeatedly, they accidentally entered the wrong data. This led to a series of changes to the design of the interface such as larger buttons and simpler pages, as well as better call centre support for service users. Even the best upfront design process would be unlikely to identify all these problems in advance.

Our discussions on implementation of the innovations highlighted the operational complexities of rolling out even relatively simple digital technologies in health care. For an app like Huoleti, you need coders and software developers to correct glitches and keep the app up to date, 24-hour support to address both technological problems and to respond to peers and volunteers if needed, and people to intervene if there are safeguarding concerns. Success depends on keeping all of these support services up and running. Staff and patients quickly revert to other ways of working if they can't log on or spend time on the phone waiting for support. It's a reminder of why telehealth often fails to deliver the planned savings in labour and other resources (Henderson *et al* 2014).

Enabling data sharing

The case studies illustrate potential principles and safeguards that might make it easier to build trust, gain consent and use people's health data in appropriate ways. A number of the projects established a principle that patients or families would decide who can have access to their health data, with the ability to change access rights easily themselves. The organisations in this study are explicit about the approaches they have adopted to protecting confidentiality, for example, Patients Know Best uses a public encryption key to scramble and private decryption key to decipher communications. The patient decides who gets the private key to access their data. For children with diabetes in Helsinki, parents decide whether they wish to share live-streamed data for research as well as for their children's immediate care. The project and others supported by Sitra have committed to publicising the data rights of anyone using their technology and ensuring that patients remain in charge of their data, who has access to it, and how it is used. Where patients agree to share data for research, Sitra commits to ensuring that the benefits accrue to patients and communities rather than private interests.

Radical use of technology

The Harvard academic Rebecca Henderson has documented the bias towards conservatism in the development and adoption of innovation within established organisations. Organisations are more likely to develop and adopt innovations that fit neatly within existing structures, such as the divisions responsible for

different design or manufacturing processes. They are also more likely to develop and adopt innovations that fit within the organisation's history and culture (Henderson and Clark 1990).

In health care, one implication of this is that the types of innovations most likely to spread easily and quickly are those that fit within the existing structures, such as teams dedicated to specific diseases, and those that fit within established cultural norms, say the historical balance of power between doctors and those in their care. While digital innovations have the potential to deliver radical change, most electronic patient records systems have so far replicated the dynamics of the paper-based systems they replaced, with doctors deciding whether or not patients can see their own health data and if they are to be trusted with all of the information on their care. This suggests that the challenges of implementing radical technological innovations for long-term conditions and other health conditions may be much greater than, say, simply defining the problems faced by health care professionals and services, connecting digital entrepreneurs with health services, ensuring user-friendly design or developing an effective strategy for ensuring widespread adoption.

Given these challenges, these case examples highlight the continued importance of bespoke funding streams to support the development and spread of transformative innovation for people with long-term conditions among others. If there is a powerful bias to conservatism, there is little reason to believe that NHS commissioners or providers will automatically be motivated to fund the types of innovation that deliver radical and desirable changes in care. Almost all the case examples relied on seed funding from government and many are still looking for sustainable long-term funding models.

If health care services want to harness the full power of technology, these examples highlight the importance of ambitious design processes, where entrepreneurs, health care staff and patients think as creatively as possible about how they might transform services. These case examples also highlight an important role for cross-cutting agencies such as the AHSNs in England, innovation funds such as Sitra in Finland and innovation centres in universities such as Aalborg, in convening partnerships and structuring ambitious, exploratory innovation processes – which start with a careful interrogation of the needs of patients and communities.

5   Developing digital services after Covid-19

After many years of slow progress, primary care, community and hospital services in England moved almost overnight to delivering online services during the first months of the Covid-19 pandemic. For understandable reasons, the focus was on making these changes as quickly as possible. There was no time for the governance processes, engagement with staff and service users, or the processes of evaluation and incremental improvement that are normally considered best practice in the implementation of innovation in health care.

When the pandemic is over, there will therefore be a strong case for structured processes, like those described in this paper, to evaluate the impact of these service changes, beyond simply responding to the pressures of the pandemic. Like other changes, there is already anecdotal evidence that moving primary care and hospital outpatient services online has delivered benefits for staff and service users. But this is far from detailed evidence on the impact of the changes. Without appraisal, the risk is that effective innovations are not sustained, harmful changes are retained because they offer superficial attractions, or services fail to refine innovations or exploit their full potential.

As many have argued, the approach to evaluating the impact of service change in health care needs to be fundamentally different to evaluating new drugs or treatments. Unlike a new drug, there is often limited value in trying to determine, in the absolute, whether a service change such as moving services online is beneficial or detrimental. There are so many different parameters and there is scope to introduce service change in many ways, leading to wide variation in impact. Instead, as some of these case studies illustrate, the focus needs to be on evaluating which aspects of the approach delivered benefits, for whom and in what circumstances, and identifying with staff and service users what further refinements are needed to generate the full benefits and mitigate downsides – a model of appraisal closer to continuous improvement than a clinical trial (Dixon-Woods 2014; Pawson and Tilley 1997).

- These case studies also highlight six categories of sub-questions that health care providers might consider as they appraise recent service changes. Digital technology creates opportunities to adapt staff roles and bring staff across services together as integrated teams to deliver patient care. It becomes possible to do things that were extremely difficult in a face-to-face system, such as bringing a new professional into an online consultation or introducing a patient directly to staff in another service. Have NHS providers exploited the full potential of new technology to deliver joined-up, team-based care, or is there further to go?

- Digital technology has the potential either to undermine or support the relational aspects of care. Have providers designed new online services in ways that create closer relationships rather than weakening them, for example, by supporting easier and sustained communication between service users and a small team of care givers? It is harder to 'eyeball' a patient to assess their overall health in a video consultation or spot the signs of abuse without a home visit. As they move services online, are health care staff focusing resources on face-to-face contact where it really matters?

- Digital technology can help to embed traditional forms of interaction between professionals and patients or it can be used to establish more balanced and effective therapeutic relationships. Have health care providers taken the opportunities offered by digital technologies to give patients greater control over their care, for example, access to their own data, the right to decide who sees their data and how it is used, and choices about when and how they access care? Will the approaches adopted help to establish greater trust and give service users greater confidence that they can share data with health services safely?

- Has the move to online services allowed staff to deliver more holistic care that addresses the psychological and social aspects as well as the biomedical aspects of illness? Or, as some fear, has the move encouraged health care staff to focus more narrowly on the biomedical aspects of care? Is there scope to harness digital technology to deliver more holistic care, for example, by helping to connect service users with their peers and communities, as well as improving how medical care is delivered?

- Have providers gathered feedback and assessed the impact of moving services online for particular social groups such as people from ethnic minority groups, people living in deprivation, people experiencing homelessness or older people? What practical steps could be taken to ensure

that these groups benefit from new combinations of online and face-to-face services?

- In the first half of 2020, a priority for health services was simply to reduce face-to-face contact while moving existing appointments online. As online services are embedded, are there opportunities to think more radically about how care can be delivered in future, for example, developing more experimental models of care or approaches that better reflect the nature of many long-term conditions?

6 Full case studies

TeleCare North

In Denmark, 15 per cent of adults over 45 have COPD, with around 23,000 hospitalisations and 3,700 deaths from the disease every year. By the mid-2000s, COPD had become the third greatest contributor to poor health in Denmark, as measured by reduction in disability-adjusted life years. It was also a significant drain on Denmark's health care resources. A quarter of patients with COPD are admitted to hospital within the first month of diagnosis and COPD patients account for one-fifth of hospital admissions. A new telecare technology that was set up in Aalborg University and is now funded for use across the whole of Denmark offers a new approach for treating this disease.

In the late-2000s, a district nurse completing a PhD in telemedicine at Aalborg University in the north of Denmark highlighted the impact and costs of repeated hospitalisations for people with COPD. She highlighted the proportion of COPD patients whose lives were consumed by visits to GPs, community health centres and hospital outpatient services, and the number revolving in and out of hospital wards when they suffered an exacerbation.

There were obvious opportunities to improve the quality of care for these patients. Poor communication and co-ordination between hospital services, community health centres and primary care practices, in part because these services were using different electronic records systems, often meant that patients didn't receive continuous care. The researchers saw opportunities for improvement through ensuring better communication between services and more consistent monitoring and rehabilitation after discharge from hospital. The limited involvement of patients in the care process, coupled with their lack of knowledge of how to effectively manage their condition, increased the risk of deterioration. There were also opportunities to improve outcomes by better involving patients in their care, helping them to manage their conditions better at home and in doing so address some of the psychological effects of coping with a cyclical and debilitating long-term condition. There were also opportunities to improve people's lives by reducing the number of routine follow-up appointments at centres away from their homes, something that placed significant burdens on people and their families.

In 2008, a group of clinicians and researchers specialising in health technology at Aalborg University launched Telekat, a project that would attempt to resolve

these difficulties of using telemedicine. They spent their first year working with groups of patients, health care staff and technology companies to understand people's challenges and how they might use telemedicine to address them. They also built a partnership with the Danish Lung Association and others to advise on how best practice treatment could be adapted for delivery through telemedicine and how to support patients in self care.

In 2009, the group recruited more than 100 patients with severe or very severe COPD to participate in a two-year trial of telecare support. The group continued to receive standard health care support including routine appointments with GPs, specialist nurses in local health centres and hospital specialists depending on their condition. In addition, patients received a 'telekit' including a tablet, a blood pressure monitor, a fingertip pulse oximeter and a precision scale. Staff taught them how to collect vital signs using the devices and input the data into the tablet, including systolic and diastolic blood pressure, heart rate, weight and oxygen saturation. Staff also gave patients education, developed with the Danish Lung Association, on self-managing their condition and performing preventive exercises such as stretching neck muscles, exercising the chest cavity and walking to improve their symptoms. Once they had received training, patients could access a wide range of information through a web portal and interact with peers in an online forum.

Once enrolled, patients would become more active participants in their own care and take on the data collection functions previously carried out by nurses. Once patients had inputted their health data, the tablets forwarded the data to an online web portal where it could be accessed by patients and health care staff. District nurses monitored whether the data is within normal thresholds, using a traffic light system. Staff provided personalised feedback to the patient by email or on the phone. They were able to maintain more regular contact and monitor a patient more carefully if symptoms worsened or complications arose, and could initiate treatment or referrals if the data deviated from expected values. Patients could also contact health care staff more easily than in traditional services through a web portal, email or telephone. The result was that patients received much more frequent contact and monitoring than under traditional treatment protocols and much faster intervention if there were signs of an exacerbation, including faster prescription of antibiotics or hormone therapy.

One feature of the programme was the active involvement of researchers and structured evaluation throughout each piloting phase. This was been part of a concerted effort in Denmark to address gaps and ambiguity in the evidence base for telemedicine. During the first phase, researchers at Aalborg University conducted a randomised trial comparing the patients in the pilot with patients who continued only to receive traditional health care treatment. Patients in the

pilot programme completed RAND's 36-item short form health survey, a set of questions to assess people's quality of life, at the start and end of the programme. Despite having less face-to-face time with health care staff, 71 per cent of patients reported an increased sense of security. In addition, 61 per cent reported increased control over their condition and 50 per cent reported increased awareness of their symptoms and ability to address them (Lilholt *et al* 2016*)*.

Researchers found that rates of readmission to hospital for patients in the programme were 54 per cent lower than for those in the control group and estimated that for patients with severe COPD, the intervention reduced overall health costs by 7,000 Danish Kroner (approximately £800) per year. For those with very severe COPD, it reduced costs by 9,000 Danish Kroner (approximately £1,030) per year (Witt Udsen *et al* 2017).

The data appears to confirm theories on the positive psychological effects of self care for people with cyclical long-term conditions, including reducing helplessness and increasing sense of control. In interviews, patients highlighted seeing data presented in simple graphics, receiving feedback from health care staff and sharing knowledge with other patients as important factors for increasing involvement and motivation to manage their care. One patient explained, 'Seeing my data on the web portal gives me a better understanding of how to exercise and interpret the development of my symptoms.' Patients also reported being more motivated to engage in preventive exercises. For both patients with severe and very severe COPD, there was a measurable improvement in quality adjusted life years.

During the piloting phases, health care staff were often sceptical of the ability of patients to contribute to the design of the programme and to play a major role in their care. In reviews, however, staff highlighted a dramatic change in how they worked with patients. Staff explained that patients had moved from being passive recipients of care to active partners who were playing a central role in the care process. A number noted that they felt more like coaches than care givers: 'I feel that the COPD patients are getting to be more active and motivated to do training at home. I feel like a coach for them.'

This evidence from the Telekat pilot justified expanding the programme, renamed TeleCare North to operate on a permanent basis for the whole of the Jutland region, with continued oversight from researchers at the Aalborg University but operational management of the programme by regional authorities and the 11 participating municipal authorities. As the programme has expanded, researchers have continued to carry out detailed evaluations of its impact, leading to refinements in how the programme is delivered.

At the end of Telekat and during the initial years of TeleCare North, researchers carried out surveys, structured interviews and workshops to assess the usability of the telekit. The first survey found that 9 out of 10 patients found the telekit easy or very easy to use. But despite this, significant numbers of patients stopped using telemedicine during the initial Telekat pilot and once TeleCare North had been established, something that typically happens when patients struggle to operate the technology, when it doesn't respond directly to their priorities and needs, or when it doesn't fit with their daily routines. Most of the COPD patients in the programme are older people and a large proportion are from more deprived socio-economic groups who typically have lower levels of health and technology literacy. Many have poor eyesight and reduced fine motor skills.

More detailed reviews highlighted small practical problems that made it difficult for some COPD patients to engage in telecare. Patients found it difficult to remember their usernames and passwords and log in to their tablets without calling for support. There were delays between receiving training and receiving the telekit. Some patients found it hard to read the information on the tablet and distinguish particular buttons from each other when entering their data. Older people with COPD may have poor circulation, longer fingernails and calloused fingers, something which may have made it harder to operate a touchscreen. When they pressed the touchscreen multiple times, it resulted in answers and measurements being input incorrectly. These reviews led to a large number of changes to the interface, including a simpler layout for each page and larger buttons to make it easier to input data (Lilholt *et al* 2016).

The project has highlighted the need for iterative, circular processes for testing operation of the system with professionals and service users, making changes in response and assessing the impact. Health care professionals and experts in digital technologies were interested in the system's general functionality, for example, its effectiveness in providing feedback to health care staff and preventing errors. Service users were more interested in practical questions such as how easy or difficult it would be to set up the equipment every few days, how time consuming it would be to take measurements and input them, how easy it would be to correct mistakes and how frustrating it would be to seek support. There was no obvious way to predict some of the problems that arose. The only way to uncover these issues was to have structured and repeated processes for studying how patients actually experienced the system.

The programme also appears to have delivered substantial benefits to how different health services, patients and their families work together. Patients would normally receive care from multiple services with limited sharing of information or joint working between them. In the programme, GPs, nurses,

hospital specialists, patients and their families use a shared web portal that brings together all the patient's medical records, their treatment plan and their health data. GPs, district nurses and hospital specialists participate in monthly teleconferences to review patients' treatment plans and decide how best to use their combined resources. The programme is encouraging health care staff to play new roles and to collaborate and share information in new ways. Hospital specialists are spending more of their time supporting GPs and district nurses so that they can provide rapid support in the community rather than giving direct treatment when conditions worsen. For Helen Rasmussen, the project manager responsible for the TeleCare North programme, the main challenge was not putting in place remote monitoring, but the changes to practice needed to ensure that monitoring led to appropriate response for health staff.

Since 2019, the Danish Government has mandated and funded the establishment of permanent telehealth programmes for COPD patients across the whole of Denmark, inspired by the TeleCare North model. Researchers at Aalborg University are completing a randomised controlled trial to assess the impact of a similar model of telehealth, using the same portal and some of the same equipment, for patients with heart disease.

Patients Know Best

The UK-based social enterprise, Patients Know Best, provides an online patient portal offering patients and health care staff a safe and secure way of exchanging information and giving patients access to their medical records. One key feature of Patients Know Best's approach is to put patients in charge, ensuring that they can access all the information about themselves in real time. Patients decide who else can access their information and allow new health care staff to join their team when needed, for example, when a GP or accident and emergency staff need to see their care plans.

Mohammad Al-Ubaydili, Patients Know Best's chief executive and founder, was diagnosed in his teens with a rare immune deficiency that made it harder for his body to fight off infections. His family began to keep detailed records of his care, in part so they could educate new doctors on his condition. Mohammad described the moment he realised that he and his family were the experts on his condition: they were the only ones who had lived through each cycle and been at every medical consultation. He also described the importance of taking control over his own care. It was only when he learnt to give the injections himself that he gained sufficient independence to travel and study at medical school.

Mohammad started work on design of the Patients Know Best portal in 2008. From his work in the UK and US health systems, he believed that most models for managing patients' health records had been designed with the interests of professionals and institutions in mind, rather than patients. For example, most models were designed to allow professionals to manage information about patients' health rather than giving patients automatic access and control. Models were designed to meet the needs of individual health care organisations, rather than allowing patients to share their information with other health care providers, let alone their social workers or teachers at school.

With Patients Know Best, he aimed to develop a system where patients control the data and use it according to their needs. Patients who join Patients Know Best receive a unique identification number and log into the portal on a smartphone or computer. What they see is a little like a medical version of a Facebook page, with notifications, posts about recent events and icons for test results, medication lists and care plans. Like Facebook, patients decide who can join their group and access their information. They can give access to staff across a health system such as their GP, hospital doctors and community teams. They can also give access to anyone outside the health system, such as family members and carers. Patients can use the system to set up and see upcoming appointments, contact health care providers, see test results, keep a diary and

add information about their conditions, including through linked devices such as blood pressure, blood glucose and heart monitors.

One important feature of Patients Know Best is that patients are genuinely in charge of their data rather than entrusting it to professionals or an IT provider. Only the patient has automatic access to their information and the patient can give others the right to see their information or take that right away. Each patient's record is encrypted with a public key and decrypted with a unique private key that the patient controls. Patients Know Best doesn't have the private key and cannot access patients' data in any way.

During the early phase, Patients Know Best worked with a small number of enthusiastic hospital consultants to demonstrate the benefits of the portal. Susan Hill, a paediatric gastroenterologist, runs Great Ormond Street's national service for children with intestinal failure. These are children who cannot eat food and depend on artificial nutrition through a tube. Susan described her worry when children left her clinic, knowing that when they had an emergency, health care staff in other services would not be able to access up-to-date information about their condition and treatment plan. One of the attractions of Patients Know Best was simply ensuring that parents could access all the letters she had sent on their mobiles and show them to staff in the emergency department when needed.

When Susan had sent her first five letters to patients through the Patients Know Best portal, she received a message from one of her families pointing out an error. There is evidence that doctors' letters routinely contain errors (Garåsen and Johnsen 2007) but this was the first time in 15 years that one of Susan's families had contacted her about one. It highlighted both one of the reasons why doctors are nervous about open sharing of patient records and the potential benefits. Doctors are understandably worried that if they share information openly, people will be able to spot mistakes and criticise their work. But transparency opens up the possibility of real team working between health care staff and their patients and families, using everybody's time and resources to improve care. Susan's response was to send out more letters through Patients Know Best so that the families could work with her to get things right.

Another surprise was the impact on communication between health care staff and their patients. Susan and her team had feared an unmanageable volume of communication with families. In practice, the number of telephone calls and messages went down. So too did the time spent trying to chase people by phone, leaving voice messages and missing the return call. Parents could leave a quick message during the night if their child was unwell and know that the nurses would see it when they arrived at work in the morning. Staff could check

online that parents had received and opened messages, rather than phoning repeatedly to check that important information had made it through.

Since 2016 AHSNs have helped to develop the evidence base for Patients Know Best and to support adoption across the English NHS. For example, the Kent, Surrey and Sussex AHSN has supported the introduction of Patients Know Best for 4,000 patients with inflammatory bowel disease who receive treatment from Surrey and Sussex Healthcare NHS Trust. At present, more than 5.2 million patients across the UK have Patients Know Best health records, making it the most widely adopted patient portal in the UK.

Mohammad reflected on 11 years' experience of supporting the adoption of Patients Know Best for patients in different local health systems. In the early phases, they needed to work with forward thinking clinicians such as Susan to test the model and build the evidence base. However, it was not possible to make rapid progress by persuading individual teams to adopt Patients Know Best one at a time. Instead, Patients Know Best now asks health care providers to establish a governance committee to review the evidence and make an adoption decision for the organisation as a whole.

Once organisations have decided to adopt Patients Know Best, patients are extremely quick to sign up to use the portal. For a large hospital, it is common for 10–15,000 people to register to use the portal within four months. Patients Know Best insists on providing all health records and test results to patients through the portal as soon as they have been entered in medical records, without making modifications or exceptions, which triggers other changes in services. In adopting organisations, there is often a moment of panic when doctors realise that patients can access their records and are looking at test results before the doctors have had time to interpret them. Once the panic subsides, staff at Patients Know Best engage with clinical teams on how they might adapt their work processes now that they can communicate with patients in new ways, for example, switching from routine 'just-in-case' appointments to 'just-in-time' appointments when patients really need to come to the clinic, and providing information through the portal so that people can self-assess, manage their conditions better on their own and know how best to access support if things get worse.

Patients Know Best releases cash savings simply by avoiding the postage costs of sending out large volumes of letters to patients. When health care staff send a message through the portal, 50 per cent of patients read the message within 2 hours and 75 per cent read it within 48 hours. However, the most significant savings come from clinical transformation. Following the introduction of Patients Know Best for patients with inflammatory bowel disease, Surrey and Sussex

Healthcare NHS Trust saw a reduction the number of outpatient attendances and inpatient admissions and shorter waiting times to see a specialist during an exacerbation, while patients reported greater confidence and better control of their conditions. At North Bristol NHS Trust, the introduction of Patients Know Best for patients suffering from severe trauma dramatically reduced unscheduled attendances at GP practices.

Remote glucose monitoring and data analysis for children with diabetes

Helsinki University Hospital and partners within the CleverHealth Network are using remote monitoring of insulin pumps and blood glucose sensors to improve treatment and help families to care for children with type 1 diabetes. They are now building a system to enable the safe sharing of live-streamed health data so that health care staff can monitor children remotely and intervene immediately when care is needed. They are also planning to apply machine learning and other techniques that make it possible to analyse large volumes of data so that they can better predict and prevent hyperglycaemic events.

Finland has the highest prevalence of type-1 diabetes in children in the developed world, more than twice the rate of the UK, the likely result of autoimmune and environmental factors (International Diabetes Federation 2019). For parents and children, the impact of the diagnosis can be devastating. Parents need to monitor their children's blood glucose levels day and night. They may need to take difficult medical decisions every few hours, usually without immediate medical support. If a child's blood glucose levels are too high, they can lose consciousness. If their blood glucose levels fall too low, this can cause irreparable tissue damage. At night, it is often hard to know whether a child is asleep or in a coma. Parents need to oversee use of insulin, a potentially lethal drug. Children may be unable to maintain their school routines, activities and social lives. Many parents struggle to cope, take sick leave or stop work entirely.

Since the mid-2000s parents and children with diabetes in the Helsinki area have been able to join a Nightscout network, which allows them to monitor their children's blood glucose levels remotely. The system was put together by software engineers, many of them parents with diabetic children, who were frustrated by existing technology and the pace of innovation and improvement. Children already had digital sensors that allowed them to monitor glucose levels continuously, rather than making a pin prick every few hours. One of the most common is Dexcom's transmitter and sensor which children wear on their abdomen, with the transmitter on the outside and the sensor inserted just below the skin. But the parents had no way of transmitting this data beyond a pager a few metres away. The parents effectively hacked the Dexcom device so that it can upload the data to a server via the internet, allowing them to monitor their children's blood glucose on a smartphone or a smartwatch.

The combination of remote blood glucose monitoring and digital insulin pumps has transformed families' lives. As well as the blood glucose sensor, many children wear a small electronic insulin pump, attached to their bodies with a thin tube, which automatically delivers small doses of insulin in respond to blood

glucose readings from the sensor. Parents and children no longer need to carry out repeated pin pricks, calculate insulin doses or administer insulin through injections. Parents can support the child's diabetes care remotely and there is no need to constantly worry or call the child to ask about their glucose levels. Checking blood glucose remotely means that for children with diabetes, their world doesn't revolve around the disease even if they are being monitored continuously. Parents can keep tabs on their children's glucose levels during school sports practice while they are at work. They can go to bed knowing that if they need to help in the middle of the night the sensor will wake them up.

Päivi Miettinen, the lead consultant for children's diabetes at Helsinki University Hospital, explained how her team began working with these tech-savvy families to make use of their data within health care services. The initial focus was simply on making the parents' system a little safer through monitoring by medical staff. Päivi and her team asked parents to email them data collected on their laptops on their children's blood glucose levels and insulin dosages. They reviewed the data to spot trends and advise parents on better management of their children's diabetes, for example, if there are particular points in the school day or week when children's blood glucose was high or low.

In Helsinki and other areas that have since adopted the technology, the data has shed new light on the disease. For example, it has revealed greater variability between children with diabetes than previously thought, with groups of children having distinct forms of disease requiring different approaches. It has also highlighted the importance of faster intervention to reduce to the minimum variation in blood glucose levels rather than simply achieving on average normal haemoglobin A1C levels. The data has made clear that some children are outliers: they do not respond to treatment in the same way as most other children and require much higher insulin doses than previously believed.

For Päivi, the data has also brought home the differences in the nature of the disease and appropriate treatment strategies within different families. Each family has its own strengths and weaknesses, with particular patterns of family life that help to control or exacerbate diabetes. More granular data has given health care staff a basis for developing treatment models that work for a particular family with particular tendencies and constraints. For example, they can identify the routines, activities, forms of exercise or eating patterns that have a particularly positive or negative impact on a child's health.

For children with diabetes, there are particular risks of a hyperglycaemic event during the school day. Children forget to have snacks or proper meals during busy days and compensate too late. With the data, Päivi and her team were able to review how well schools were supporting newly diagnosed children over the

course of a school term and give them extra support if needed, for example, on how to check children's monitors, when to give them some fruit or when to call their parents or health care staff.

Over time, this use of data had a dramatic impact on the number and timing of face-to-face hospital appointments. Rather than seeing children every three months, health care staff can see those whose conditions are stable once every six months, once a year or no longer schedule any routine face-to-face follow-up appointments. Parents appreciate not having to take so much time off work or to organise childcare for other children to attend hospital appointments. Children appreciate less disruption to their school days and feeling less like they are different to other children. For health care staff, this hasn't reduced workload but has substantially changed how they spend their time. Health care staff are able to focus on the children and families who most need intensive support and, as above, to spend more time creating an ecosystem of parents, family teachers and others with the skills and confidence to help children manage their diabetes.

However, there are still significant limitations in the system. Until recently, health care staff received files every month or so from parents with data on their children's blood glucose levels and insulin doses. For Päivi, 'It would be great to receive the secure data from the insulin pump and glucose sensor directly to my desktop. This way I can help parents improve the child's glycaemic control even better.' While better data has revealed new patterns, it is still an extremely difficult task to predict and respond pre-emptively to likely changes in children's blood glucose levels. Applying machine learning and other tools to much larger volumes of historical data may shed new light on how to manage the disease.

Since April 2019, staff at the hospital have been working with patients develop a secure system for sharing real-time data on children's health with the hospital directly from their sensors and smart phones. The work forms part of a series of projects, sponsored by the Finnish innovation fund, Sitra, to build the foundations for a fair and effective data economy, where the public is willing to share personal data with public and private providers and where this data is used in the interests of individuals and communities.

While it might seem simple, there are huge practical complexities in agreeing how to share large volumes of children's personal health data with health care providers and other organisations and the parameters for using it. As Päivi explained, parents and children want to support better partnership working with health care organisations and interrogation of data to improve treatment. But at the same time, parents and children do not want health care staff to be able to invade their lives. Teenagers may be concerned about institutional surveillance. The project raises questions including how to secure and maintain consent; how

to transfer, store and interrogate data securely; the purposes for which the data can be used; and how the benefits should be shared.

Since spring 2019, the partnership has developed an integrated authorisation process so that parents can give their consent for different organisations to transfer and store their children's health data. It is the parents who are in control and decide which organisations can hold the data and how it is used. The partnership has also developed an open source code solution, which should enable a seamless, direct transfer of data from one online service to another. This should allow health care staff to monitor live data and may create opportunities to intervene in new ways, for example, contacting parents and teachers immediately to change children's diet, activities or treatment. It will also allow staff to analyse large volumes of data in the hope that they can identify patterns and predict hypoglycaemic events.

Huoleti

Finnish start-up Huoleti uses a mobile app to crowdsource care and support for patients coping with severe illnesses, as well as support for their families and carers. Patients and carers can use the app to build a network of supporters, seek advice from people who have experienced the same disease, stay connected with their communities and ask people for help with daily tasks.

In 2016, Carita Savin secured seed funding from Kertomalla Paranee a partnership between innovation agencies, public sector hospitals and private providers, to develop new forms of support for cancer patients in Finland. The partnership found that cancer patients received high-quality medical care, but between appointments and once they had completed medical treatment they received very little support. Health care services did not connect patients or their families to peers and people felt they were the only ones to go through the disease. When people are seriously ill, it is assumed that friends will rally round. But its research suggested that during serious illness people get disconnected from their friends and communities.

The partnership also identified limitations in existing approaches to innovation in health care. Technology entrepreneurs and health care professionals developed innovations that reflected their own interests rather than starting with the priorities of service users. Entrepreneurs wanted to apply particular digital tools, while health care staff focused only on the medical treatment process. The result was large numbers of innovations that did not really address the needs of patients and families.

Carita and colleagues worked with service users and health care staff in an intensive two-week design camp to understand people's needs and work out how to connect them with their communities. Their initial focus was on understanding patients' and families' emotional world and the practical challenges of coping with serious illness. They followed a structured process to map the needs and priorities of different stakeholders throughout the course of illness including during the diagnosis phase, the treatment phase, and after treatment.

In one-to-one interviews, patients explained how surprisingly difficult it was to build or maintain support networks when seriously ill. People stop work, their social routines fall away, and it is often much harder than expected to stay in touch with friends. One patient explained, 'After the cancer diagnosis, everyone said "Just call me any time." They seemed to be as frightened as I was, and I never called.' In other cases, friends would continue to visit, but there would be awkward conversations focused entirely on the patient's illness, despite patients not wanting their lives to be consumed by the disease. Rather than rallying

round, some friends dropped off the radar entirely. People can be awkward when confronting those with serious illness. They don't know how to manage the first encounter, they back away, and as time passes it becomes more difficult to reconnect.

The initial research highlighted the potential impact of relatively simple forms of support, which had a major impact for patients, but were neglected by health services, for example, helping connect patients with peers, making it easier to ask for help and to obtain advice. It led Huoleti to focus on solutions to three common problems that were significant for patients but neglected by health care and other existing services: matchmaking to bring together patients and families with peers with similar experience; making it easier for patients and families to ask for help, and for volunteers and service providers to offer help; and creating personalised data so that patients and families can easily obtain accurate information about how to manage their conditions.

Carita launched Huoleti in 2017, initially as a service to help cancer patients build support networks. In its second year, Huoleti ran 20 pilot projects testing the service for patients with cancer, different forms of bowel disease, musculoskeletal disorders and neurological disorders. Huoleti currently provides services for cancer patients and is developing services for people with inflammatory bowel disease and to support healthy ageing.

Patients and families download the app and use it to ask friends, peers with lived experience of the condition and volunteers for support. They can use the app to invite friends to join their support network. They can also use a map on the app to find volunteers or peers who are willing to provide support in their local area. Rather than contacting people individually, patients can simply tick items on a checklist of issues they would like help with, such as meeting for a chat, going for a walk, help with the groceries or transport to hospital. Carita explained: 'The request goes to everyone in your network, so you don't have to ask people separately. It lowers the barrier for asking for help and no one has to say that they can't help. Instead those who can help reply to the request.' Asking friends to do practical tasks such as helping with a drive to the hospital or shopping seems to make it easier to stay in contact. Helpers come round with the groceries and then stay for a coffee and a chat.

As well as creating a network of family and friends, patients and families can use the app to connect with trained volunteers and peer supporters in the local area, using a map for patients and families to find volunteers close to their homes. These volunteers need to have been trained in providing support and to be members of a volunteering organisation. Before the app, patients were likely to have no contact with others who had had the disease. Health care staff rarely

have the time or the systems to help patients connect safely with peers. With the app, patients can manage a network of patients and families can identify peers and share experiences of coping with the illness. Patients are able to control the discussion, deciding whether to start or join discussions and who to involve. As one patient explained, 'Even with my family supporting me, only somebody who has experienced the same can fully understand how devastating it is.'

One thing that surprised the founders was how much family members and friends need support when a loved one is ill. Spouses are struggling to understand what is happening to their husband or wife. They desperately want to help their loved ones but don't know what to do. Like those who are ill, they need to know that others have gone through the same situation and survived. They also need to be able to ask their peers questions they might struggle to ask their partner, for example, what they should do when their partner is in pain, or whether it is ok to touch them. Friends need advice on how to engage, for example, how to make the initial contact, what they should say and how to offer useful support.

A number of things are needed for the system to work. Huoleti requires peer support workers and volunteers to have had training and to be members of an accredited volunteering organisation. Volunteers and peer supporters can contact Huoleti 24 hours a day for support or advice. In principle Huoleti will intervene if there is evidence that a participant has breached its community standards, although this has happened only very rarely so far.

There are currently 10,000 patients using Huoleti in Finland and across Europe. Up until now, funding has come primarily from pharmaceuticals firms or hospitals that want to ensure that patients have sufficient social support alongside medical treatment. For health care staff, it is particularly valuable to be able to ensure that everybody involved in supporting a patient has access to a consistent set of information on how to help them, for example, what to do if their pain increases or in an emergency. Health care staff also value the ability to connect patients with peers to help solve everyday challenges – how do you manage a long trip to hospital when you need to go to the toilet every 30 minutes? These are issues where health care staff are sometimes unsure what to do but where peers with lived experience are well placed to offer practical advice.

Huoleti is collecting data on patients and families' experience of using the app and the impact on their recovery. Patients report that the app helps them to stay better connected to their friends and communities. While this is still a relatively new service, data collected so far suggests that service users are better able to

maintain relationships, suffer less from loneliness, maintain a greater sense of control over their lives and are more optimistic about the future. There is also evidence that patients follow their medical regimes more precisely, experience greater wellbeing during illness, and make a faster recovery.

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8 About the author

Ben Collins joined the King's Fund in 2015 as a project director, working for the Chief Executive and across the Fund, including on policy and supporting the NHS in developing new care models.

Before joining the Fund, Ben worked as a management consultant. He has advised central government and the national bodies on a wide range of issues including economic regulation, provider finance, the provider failure regime and new organisational models. He has also worked with large numbers of NHS purchasers and providers on strategic and operational challenges.

In his earlier career, Ben was a fast-stream trainee and manager within central government and an adviser at the European Commission. He has academic training in industrial economics and business strategy.