HCI for health and wellbeing: challenges and opportunities

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Highlights

- A data lifecycle highlights important complementary interactions with health data
- Challenges for HCI in health lie in the scale and complexity of health and care
- Highlights role of digital mediating between people and medical technologies
- To have impact at scale in health, HCI needs to complement other disciplines
- Health and wellbeing technologies need to fit individual and care contexts

HCI for health and wellbeing: challenges and opportunities

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Abstract

In terms of Human–Computer Interaction, healthcare presents paradoxes: on the one hand, there is substantial investment in innovative health technologies, particularly around "big data" analytics and personal health technologies; on the other hand, most interactive health technologies that are currently deployed at scale are difficult to use and few innovative technologies have achieved significant market penetration. We live in a time of change, with a shift from care being delivered by professionals towards people being expected to be actively engaged and involved in shared decision making. Technically, this shift is supported by novel health technologies and information resources; culturally, the pace of change varies across contexts. In this paper, I present a "space" of interactive health technologies, users and uses, and interdependencies between them. Based on a review of the past and present, I highlight opportunities for and challenges to the application of HCI methods in the design and deployment of digital health technologies. These include threats to privacy, patient trust and experience, and opportunities to deliver healthcare and empower people to manage their health and wellbeing in ways that better fit their lives and values.

Keywords: digital health; medical devices; health IT; patient empowerment; patient safety; human factors; complex adaptive systems

1. Introduction: HCI for health and wellbeing in 2019

Digital technologies are now playing a major role in the delivery of healthcare and in individuals' experiences of health and wellbeing management. The overall "space" of health and wellbeing issues that can be addressed by digital technologies is vast, and the number of and variability between users of those technologies is also large. Within HCI, many studies have reported on user needs for particular situations (e.g., Anderson and Woodroffe, 1969; Rajkomar et al, 2014); on the usability, user experience and safety of particular health technologies (e.g., Edwards et al, 2008; Laurie and Blandford, 2016); and on novel interactive digital interventions in healthcare (e.g., Lisetti et al, 2003; O'Hara et al, 2014). However, the perceptible impact of HCI on healthcare practices and on the experiences of health professionals and patients has been relatively limited to date. In this paper, I review some of the reasons for this: focusing not on the usability of particular health technologies, but on the broader cultural and technological factors that shape people's experiences of health technologies in a system that is complex and adaptive (Braithwaite et al, 2018; Greenhalgh et al, 2017).

Worldwide, healthcare systems and the ways that people engage with their health and wellbeing are going through a period of rapid change. In terms of technology, these changes include the gathering and analysis of new kinds of data (genetic, genomic, other new biomarkers, as well as more behavioural, environmental and economic data); the application of machine learning techniques such as deep learning (LeCun et al, 2015) to large health datasets; uptake of novel technologies such as wearables, implantables, ubiquitous sensing devices and other Internet of Things (IoT) devices; and integration of technologies such as imaging and analytics with surgical devices. In terms of people, we see the rise of the activated patient and online patient communities (e.g., Topol, 2015); expectations that patients will be actively involved in decisions about their care (e.g., "no decision about me without me": DoH, 2012); and an increasing focus on prevention and wellbeing.

These developments are taking place at multiple levels. At an individual level, novel interaction techniques are introducing new ways for professionals and patients to engage, perceptually, cognitively and emotionally. In terms of patient "work", there are changes in the ways that people, situated within their technological, social and physical environments, manage their own health and work with health professionals in doing so. The ways in which health is "delivered" through care systems to people within a community are evolving. At a population level, our understanding of the causes of poor health and effectiveness of interventions is advancing. At the heart of many of these developments lie data and analytics, which are likely to have a growing impact on people's experiences of health technologies in the future.

We can conceptualise the different interactions and uses of health data in a health data lifecycle, illustrated in Figure 1. This shows the flow of data from the individual, shared (e.g., through shared care records or online health communities), pseudonymised, aggregated and analysed for population health research, from which findings lead to new understanding which informs future clinical practice. Information exchange [1] represents the classical clinical encounter, while [2] represents information managed by the individual and exchanged with peers (e.g., through online health communities and collaborative apps) and [3] represents the use of data for population health analysis, including the sharing of pseudonymised care records [3a] and integration with other data sources.

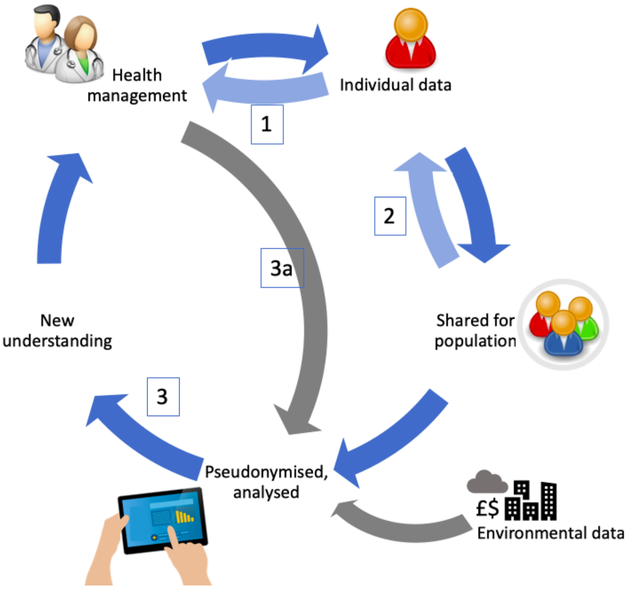

Figure 1: A simplified health data lifecycle

Data analytics can be applied throughout this lifecycle: in the analysis of trends over time for the individual, in comparing individual data with aggregated population data, and in the integration of data from multiple sources (including care records) for population health analytics. Gotz and Borlund (2016) summarise opportunities and challenges for data visualization across these phases of the data lifecycle, but a variety of other digital technologies are also essential in current healthcare. Here, I briefly review the different phases of the health data lifecycle and the digital technologies that support them, as groundwork for considering the roles of HCI in developing, evaluating and deploying such technologies.

1.1 Interactive technologies for clinical care and self-management

Many kinds of digital technologies are used to deliver clinical care and support self-management (area [1], Figure 1). These include medical devices for measuring vital signs and delivering therapies; information and decision support systems to support diagnosis and decision making; and electronic health records to record data, diagnoses and interventions. The roles of these different kinds of systems are illustrated in Figure 2. A simplified and generalised care pathway can be characterised as involving measurement, diagnosis and decision making, and the delivery of therapies (e.g., medications, radiotherapy or surgery) and monitoring (through further measurements, decisions and interventions) as needed; this care pathway is represented in the central cycle. Data from measurements, diagnoses and decisions, and interventions and their effects are all recorded in the care record – at least in principle. Conversely, data from the care record is accessed to support diagnosis, decision making and the delivery of interventions. These data exchanges are represented in the arrows linking the simplified care pathway with the care record. In practice, there are many variations, and often breakdowns (e.g., missing data, incorrect diagnoses) in this cycle.

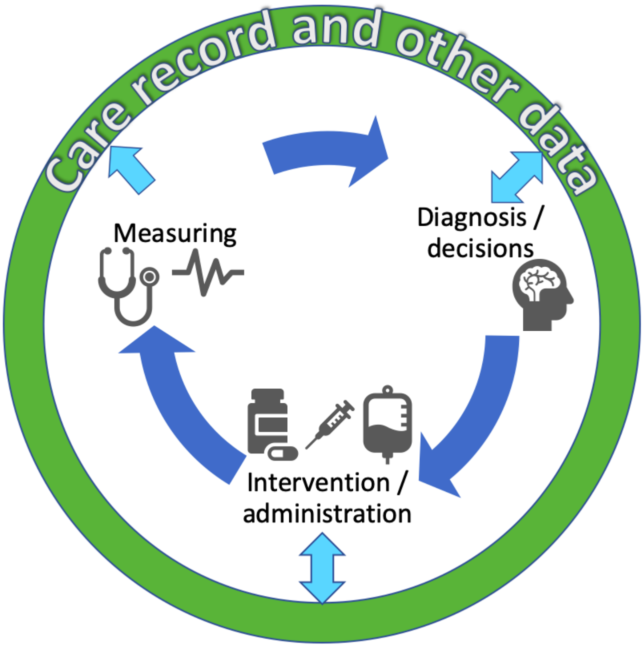

Figure 2: Data is created and accessed along the care pathway

As illustrated and described, it might appear that the primary "actor" in this cycle is a clinician; in practice, care is commonly managed by multi-disciplinary teams who bring different expertise into play, and the patient and lay carers such as family have an increasingly important role to play as more responsibility for health management is being devolved to, and claimed by, patients. These themes are revisited, together with HCI considerations, in section 2.

1.2 Online communities

In recent years, there has been a growth in online health communities (area [2] in Figure 1). Large initiatives such as https://www.patientslikeme.com/ aim to engage and support people managing a variety of health conditions while other online health communities focus on particular chronic health conditions. Davis and Calitz (2016) highlight the value of online communities in providing emotional support for people, particularly those whose clinical condition precludes them easily engaging in face-to-face support groups. Genuis and others (Genuis and Bronstein, 2017; O'Kane et al, 2016) highlight an important role for online communities and other information resources in helping people to re-find "normal" in response to a transition or progression in a health condition such as a new diagnosis, deterioration or recovery. Du et al (2017) present three versions of a prototype system, PeerFinder, that supports people in locating "people like me", based on similarities in records such as medical records; they highlight difficulties in determining which similarities matter and found that participants were more engaged and had more confidence in the results when they had access to more contextual information and were provided with greater control over similarity measures.

Topol (2015) suggests that online communities will transform the relationship between clinicians and patients by empowering expert patients; the reality is likely to be more nuanced, as some people exploit the opportunities to find "people like me" without geographical constraints while others become marginalised as online engagement becomes increasingly common; this is likely to widen the digital divides that already exist. Whilst highlighting the value of online communities in engaging people who might otherwise be marginalised, Davis and Calitz (2016) also note challenges such as managing user privacy in a way that is well understood and agreed by each user.

1.3 Interactive technologies for population health

Health data analytics (area [3] in Figure 1) involves aggregating pseudonymised data from multiple sources to deliver new population health insights. This includes personalised medicine, in which genetic data is combined with other data sources to stratify populations according to the likely outcomes of therapies (Jackson and Chester, 2015), surveillance for planning and prioritising future interventions and resource allocation (CDC, 2018), and discovery (better understanding causes of diseases and the effects of therapies) (Khoury and Ioannidis, 2014). Yuan et al (2017) report on a user study of PopHR, a population health record that included multiple visualisations (Shaban-Nejad et al, 2017). However, while there is a valuable potential role for HCI in supporting data scientists' interactions with data to inform data visualisation and sensemaking, to date there has been little user research in this area (Yuan et al, 2017).

There has also been research on visual analytics, where the role of information discovery is shared between professionals and algorithms, and visualisations are provided to support human analysts – e.g. in identifying appropriate dimensions for analysing very high dimensionality patient data (Hund et al, 2016) or in delivering geographical information systems to support analyses of disease spread (Fletcher-Lartey and Caprarelli, 2016). Fletcher-Lartey and Caprarelli (2016) highlight challenges to greater uptake of such technologies, such as limited analytical skills and uneven data availability. In a systematic review of approaches to evaluating visual analytics systems, Wu et al (2019) highlight inconsistencies in the ways such systems have been evaluated to date. Such studies highlight areas where HCI can provide valuable input, in better understanding and supporting the processes of information discovery and in developing relevant and valid approaches to evaluating visual analytics systems.

1.4 The bigger picture

Across all three areas, there have been some notable, and well publicized, success stories. For example, there are reports of user-centred design for innovative radiotherapy technology (BBC, 2018); clinical trials for mental health apps (Richards et al, 2016) and validation for data analytics (De Fauw et al, 2018). There are also initiatives integrating these areas, moving towards the "cycle" vision of Figure 1. However, there is also a lot of hype about the potential of digital technologies as vehicles of "innovation", "transformation" and "disruption", most of it implicitly assuming that people will take up the technologies and use them seamlessly.

In section 2, I present a brief history of health technologies, and particularly digital technologies for healthcare (area [1] of Figure 1); I focus on this area because it is the most complex and probably has the greatest need for HCI input. In section 3, I outline some possible visions for the future and propose ways in which HCI could contribute to the design of better (safer, more effective, more engaging) interactive health technologies.

2. How we came to be here: a selective tour through technologies for health and wellbeing

The history of health technologies and health interventions stretches back thousands of years. Over centuries, there have been innovations in medical practices that have changed people's health experiences and the nature of health professions. In 2018, in the UK, we celebrated 70 years of the National Health Service and many other countries established universal healthcare systems at around the same time. In the same year, the World Health Organisation (WHO) issued a definition of health as "not merely the absence of disease or infirmity but a state of complete physical, mental and social well-being" (Misselbrook, 2014). Coincidentally, the first stored program computer also ran in 1948, so arguably the basic building blocks for digital health technologies were created around 70 years ago, and the past 70 years have been an era of particularly rapid change. For digital health technologies, there are substantial variations in the rate and degree of diffusion and adoption across different countries and care organisations, so this narrative is indicative rather than being accurate for any given context. In the following sections, I review the history, current status and HCI issues related to various key health technologies: medicines, medical devices, electronic health records, online information resources, telecare, and digital behavior change interventions. I close this section with a systems perspective that sketches the challenges of working with these many different kinds of technology together.

2.1 Medicines and medication administration

The earliest health interventions were medicinal and surgical. Medicines prepared from plants and other natural resources have been developed over thousands of years, and apothecaries emerged in the 16th and 17th centuries, though the pharmaceutical industry is considered to have developed in the 19th century (Malerba and Orsenigo, 2015). The role of digital tools in medication administration has been relatively specialised to date, focusing primarily on managing the delivery of intravenous medications in hospitals. In this role, traditional gravity feed devices have been largely replaced, first by volumetric infusion pumps and syringe drivers that control the rate and volume of intravenous medication to be delivered, and more recently by “smart” pumps with dose error reduction software that aims to reduce the likelihood of substantial errors in medication administration (e.g., Lyons et al, 2018). In hospitals, these devices are being complemented by health IT systems to support medication ordering (e-prescribing) and patient identification. There have been studies of the effects of the introduction of these technologies on clinical work, in terms of safety and efficiency, often highlighting their role in mitigating or provoking errors and workarounds (e.g., Koppel et al, 2008; Schiff et al, 2015; van der Veen et al, 2017). While the usability of particular user interfaces can be an issue (e.g. Oladimeji et al, 2011), the larger issue is commonly the way that multiple different devices are used together, the consistency between user interfaces, and the ways they support or disrupt clinical practices in medications management.

Beyond the hospital, infusion pumps are mainly used for palliative care and other relatively simple medication regimes. While the basic usability of these devices is widely considered acceptable by those who set them up, issues emerge in the broader setting, such as ensuring that they cannot be tampered with when there is no direct clinical supervision (Vincent and Blandford, 2017) and supporting troubleshooting when anything goes wrong (Lyons and Blandford, 2018).

The challenge of helping people to manage complicated medication regimes (with multiple medications to be taken on different schedules) is starting to be addressed; for example, Belden et al (2019) present the design and evaluation of a prototype medication timeline visualisation to support clinicians in prescribing, communicating with patients and identifying potential adverse drug reactions. Focusing on patients, digital tools have also been developed to improve compliance with medication regimes through reminding, encouraging habit formation (Stawarz et al, 2014) and monitoring compliance with medication taking. For example, US regulators recently approved a digital ingestion tracking system (FDA, 2017), though this initiative has raised concerns about patient privacy and the risk of coercion (Dotolo et al, 2018).

2.2 Medical devices

The earliest (non-medicinal) health technologies were surgical knives, which evolved into those still widely used today. Various authors (e.g. Kirkup, 1981; Bishop, 1995; Kirkup, 2006) present accounts of the development of surgical tools from prehistoric times, evolving in both materials and form over time and across cultures. Kirkup (1981) notes that “tools and instruments have evolved to facilitate, extend, and refine practices where hands and fingers alone prove clumsy and inadequate or fall short.” For centuries, the major concerns in design has been usability and utility, enhancing human capabilities as determined by the physical form of the technology. It is relatively recently that interactive digital technologies have been introduced into surgery – e.g., through robotic surgery and telesurgery.

Discoveries in physics such as x-rays (1895) have made possible new kinds of health technologies such as medical imaging devices. In recent years, most health technologies have been enhanced with digital components that facilitate control and data management

(Figure 3). These generally demand digitisation of measurements (e.g. images, lateral flow tests) that originally relied on physics or chemistry (e.g., Gous et al, 2018).

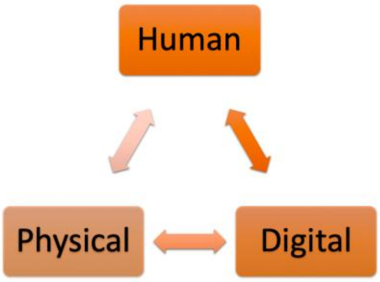

Figure 3: Most medical devices involve physical, digital and human components

As an illustrative example, I present a brief account of the development of haemodialysis machines. This technology has been chosen as a focus because, while most use is in hospitals or specialist care units, dialysis machines are also used by some patients in their own homes. The proportion of people on home haemodialysis has fluctuated over time, and varies across countries, but is typically around 10%. While other health technologies are gradually being adapted for home use (e.g., the infusion pumps discussed above), the practice of self-care in haemodialysis is already well established.

Nephrology, the management of kidney function, is mainly concerned with renal failure and disease. There are three main forms of treatment: transplant, peritoneal dialysis and haemodialysis. Haemodialysis has the greatest reliance on interactive digital technology. Haemodialysis involves a patient's blood being pumped from their body and through a dialyser (which removes toxins) before being returned to the body. Most people with chronic kidney disease need to be on dialysis for around 4 hours, at least three times a week, though more frequent dialysis is often recommended. The history of dialysis can be traced back to the mid-19th century, when the laboratory principles underpinning dialysis were established (Eknoyan, 2009). The first "artificial kidney" was reported in 1913, but it took a further 30 years for dialysis to become a feasible medical procedure (Eknoyan, 2009). Kolff et al (1944) report on the design and use of the first known dialysis machine. The functioning of this mechanical device depended on the development of three novel products: cellophane, Teflon and heparin. Hospital dialysis units became more common in the 1960s and technology that enabled people to dialyse at home was developed around the same time (Polaschegg, 2010; Haroon & Davenport, 2018). Polaschegg (2010) presents a history of the development of dialysis technology, focusing particularly on physiological and physics aspects of the therapy. He notes that the major features of haemodialysis technologies were developed in the 1980s, and that the main development in the early years of the current millennium was that "machines were beautified and were equipped with powerful computers and large color screens."

Historically, most home haemodialysis machines have been slightly smaller versions of the machines used in hospitals, but this is now changing, with more machines specifically designed for home use becoming available (Haroon and Davenport, 2018). To facilitate frequent dialysis that minimizes the disruption in people's lives, nocturnal haemodialysis has been promoted; however, uptake of this has been slow. Cafazzo et al (2010) report that key reasons for this include lack of self-efficacy (Bandura, 1997) and fear that something untoward might happen while the patient is sleeping; they focus on the importance of remote patient monitoring to address these concerns. In a user study of non-nocturnal dialysis, Rajkomar et al (2014) identified three key themes: learning to use the technology; usability issues (particularly supporting people in remembering all the necessary steps for dialysis and troubleshooting when anything went wrong); and managing safety during dialysis. In a systematic review of 24 studies, Walker et al (2015) identified both barriers and facilitators to home haemodialysis; barriers included feeling vulnerable and placing a burden on families while facilitators included better health and good professional support.

Several key points emerge from this narrative. Firstly, the very existence of this technology depends on an understanding of the underpinning science of how the body works and what intervention(s) can change the state of the body to improve health – i.e., on an understanding of key medical science. To develop a technology that functions, biomedical and other engineers needed to apply that science in practice. Skills in biomedical sciences and engineering are fundamental to the success of haemodialysis in an obvious way that skills in computer science or HCI are not, and people may not question poor user interfaces when their lives depend on the technology. Correspondingly, there has historically been little apparent pressure on vendors to offer systems with improved user interfaces.

Secondly, if digital user interfaces are to help with managing the process, physical data needs to be converted to digital and rendered in a conceptually meaningful way to the user, and the control interface needs to be usable. The needs of nurses setting up haemodialysis machines in a dedicated clinic, where they are working with several different patients each day and where the environment is tailored to haemodialysis care, are importantly different from those of a patient who is managing their own dialysis in their home, where the technology has to fit in that environment, the user interface has to be accessible to the patient (who may be managing comorbidities such as arthritis or poor vision), and there is no professional on hand to help with troubleshooting if anything goes wrong.

Thirdly, dealing with medical technology and chronic conditions is emotionally demanding – for clinicians, patients and family members (Blandford et al, 2015). Technology that is challenging to use (whether in normal operation or when anything goes wrong) adds to emotional stress, increasing the risk of compromising patient safety.

Very similar themes apply to other interactive medical devices, whether used primarily by patients (e.g. blood glucose meters and insulin pumps) or by professionals (e.g., for medical imaging or in intensive care). It seems likely that this will change rapidly in the near future. For example, regulators such as the Food and Drug Administration (FDA, 2018) and Medical and Healthcare Regulatory Authority (MHRA, 2017) have recently developed guidance on the application of human factors in medical device development. Also, there are grassroots developments such as the #WeAreNotWaiting movement of hackers adapting blood glucose meters and insulin pumps to make them better fit for purpose, effectively constructing an “artificial pancreas” for people managing type 1 diabetes (Omer, 2016). Regulatory processes, particularly for class 3 (highest risk) medical devices, limit the possibilities for iterative design as advocated within the HCI community, because they require design to be completed and approved before marketing or deployment. However, an improved understanding of the importance of usability and user experience by those designing, procuring and evaluating interactive medical devices may result in earlier consideration of HCI and human factors in device development processes.

2.3 Electronic health records, dashboards and patient portals

In contrast with most medical devices, information systems are generally "digital first" (not closely linked to biomedical systems), so the history of digital health information systems is comparatively short, though they have been developed from paper books and care records. There are two main kinds of information systems: those that contain personal data and those that do not. In this section, I consider those that contain personal data such as electronic health records (EHRs); in section 2.5, I review non-personal information resources. Within this section, I consider three areas: the EHR used by clinicians focusing on one patient at a time; clinical dashboards (drawing on EHR data) to support clinical work in areas such as intensive care; and EHR access by patients.

2.3.1 EHRs for use by clinicians

EHRs are widely used in some countries, but digital maturity is variable across regions and care organisations. In areas supported by major care providers in the US, there are regional Health Information Exchanges and EHRs that support care across primary and secondary care and are connected to (and exchange data with) e-prescribing and medication administration systems and various medical devices. In many other regions, systems are fragmented, often with multiple specialized EHRs within one care organization, with devices that work independently, and with health records that are part-digital, part-physical, relying on people to transfer data between systems as needed. In the UK National Health Service, a National Programme for IT was, for a while, the largest IT project worldwide, but was terminated around 2005 and did not deliver on its expectations (e.g., Currie and Guah, 2007). More recently in the US, there have been substantial investments in health IT that are likely to accelerate the adoption of health IT systems internationally, but to date there is limited evidence of such systems improving health outcomes or the experiences of clinicians or patients (Bui et al, 2018; Mazur et al, 2019).

One of the persistent challenges in developing useful, usable EHRs is that health data are used by different people for different purposes; even different health professionals ask different questions of the health record, and patients come with yet other questions. In a paper from the first volume of this journal, Anderson and Woodroffe (1969) discuss the care record as a paper-based set of records, noting that some parts of the record (e.g., on sexual health) were considered too sensitive to be stored as part of the main hospital record; that the nursing record was generally kept separate from the medical (doctors') record during a patient's hospital stay; and that records in General Practice were different in form and content from hospital records because they served different purposes. They proposed that, in terms of technologies for data entry and review, "the most applicable and useful appears to be the computer driven visual display unit, giving a real time facility." They outline the many purposes the care record serves and highlight the challenges of patient confidentiality if everyone who needs to access parts of the record has unrestricted access to all of it. The only means for data entry were teletypes and visual display units, but both were regarded as slow (compared to handwriting) and difficult to access (as they were not mobile). They highlight various ways in which the work of clinicians would need to change, and the necessity of employing data entry clerks.

In the same volume, Brolin (1969) describes the interface for a novel terminal for radiology reporting, highlighting the variability in what information is recorded and how, even within one clinical specialism. While there has clearly been progress in the intervening 50 years, that progress has been much slower than anyone might have anticipated, and many of the challenges highlighted by Anderson and Woodroffe remain. For example, Edwards et al (2008) describe a heuristic walkthrough of a commercial electronic health record, through which they identified over 100 usability issues; their focus is on the process of conducting the evaluation (and its value) rather than the specific issues identified. Smelcer et al (2009) focus more on the sources of usability issues such as the ways in which differences in the tasks and work styles of different clinicians affect the usability of electronic medical records; they propose various design solutions to address these issues such as customisation, being able to delegate responsibility for data entry and providing suitable data visualisations. However, in a systematic review of visualisations of electronic health data, West et al (2015) identified few established approaches to data visualization that had achieved any traction, and highlight many challenges in visualizing complex data that is used by clinicians to address many different health questions.

Taking a more abstract perspective, Middleton et al (2013) report on the outcomes from a task force to review usability issues for electronic medical records due to widespread concerns about poor fit with clinical work, inconsistent interfaces across care providers and poor usability, which risks compromising patient safety and clinical efficiency. They present ten recommendations such as creating standardized ways of testing usability and introducing ongoing monitoring of system use to learn from experiences with existing systems. Focusing on current practices in user-centred design (UCD) of EHRs, Ratwani et al (2015) interviewed representatives from 11 EHR providers. Based on a qualitative analysis, they classified providers into three groups: those with well-developed UCD processes, those with basic UCD processes, and those who believed they applied UCD but actually did not. They note that "At the policy level, the variability in UCD practices and the fact that some vendors have a misconception of UCD yet have certified EHR products in the marketplace suggest that certification requirements may need to be adjusted." They highlight particular challenges in practicing UCD as including obtaining access to conduct contextually rich situated user studies, recruiting suitably representative participants for usability studies, and being valued by senior management.

2.3.2 Clinical dashboards

As noted above, as well as being used to guide individual patient care, data from electronic health records is increasingly being used for other purposes including population health research. Another important purpose to which EHR data is increasingly being put is in supporting clinicians and others in maintaining situation awareness in settings where a clinical team is responsible for one or more patients and where each patient's condition can change rapidly. This situation holds in many settings including clinics, wards, accident and emergency departments and intensive care units (ICUs). Clinical dashboards to support situation awareness are being developed and deployed, particularly in ICUs. For example, Faiola et al (2015) report on the user-centred development and evaluation of an information dashboard to support clinicians in maintaining awareness of a single patient's condition, particularly to be aware of times when any intervention is needed. Waller et al (2019) present a systematic review of 22 studies evaluating clinical outcomes from the introduction of dashboards (some focusing on individual patient data, others on multi-patient data) in ICUs. There is great potential for user-centred design and evaluation for displays that support clinical work, particularly in dynamic contexts where clinical teams are responsible for multiple patients.

2.3.3 Patient portals

As well as clinicians accessing patient data, it is now widely expected that patients will have access to their care record through a health portal, and implicitly assumed that they will interpret it for themselves; this has required a significant rethinking of the role, format and content of the record. However, studies (e.g. Shimada et al, 2014) suggest that uptake and use of health portals is fairly low.

Most studies of health portals focus on quantitative measures such as correlations between health literacy and portal use or benefits realised (e.g. Kipping et al, 2016). Usability studies have also been reported; for example, Segall et al (2011) report in detail on a usability evaluation of one health portal, illustrating how classic user-centred design techniques can be used in this context and highlighting some basic usability issues their participants encountered. Although several studies have highlighted the likely impact of health literacy and technology literacy on patients' use of health portals, few studies have explicitly investigated individual differences in this context. In an exploratory study of the use of one patient-controlled electronic health record (PCEHR), Schneider et al (2016) used self-determination theory (Ryan and Deci, 2000) to identify four groups of users who interacted with the PCEHR, and with their clinical teams, in importantly different ways. The first group, "controllers", accessed the online care record frequently and tried to marginalise care professionals, claiming autonomy and using the care record as a means to limit relationships with the care team. The second and third groups, "collaborators" and "co-operators" both worked well with their care teams, but whereas the collaborators were proactive in accessing the care record and interpreting test results, the co-operators preferred to wait to see their clinicians and have data interpreted by them. This suggests an opportunity for creating configurable interfaces that enables people to access and interpret health data in different ways. The final group was "avoiders": people who found accessing the health record challenging, whether technically, cognitively or emotionally. More research is needed to better understand whether and how digital tools might enable some of this group to engage better with serious health issues, or what alternatives to provide.

2.4 Telecare and self-management

Telecare was being practiced with telephone support even before the arrival of digital technologies; for example, Darkins and Cary (2000) identified a journal report from 1897 of remote diagnosis – in that case, of a child being diagnosed with a croup cough. However, digital tools have made new forms of telecare possible. Examples include online triage and digitally enabled care at home (Pols, 2012), video conferencing in primary care (Liaw et al, 2019), the use of chatbots to mediate selected aspects of care (Palanica et al, 2019) and the introduction of AI technology for triage and diagnosis. With these, those with uncomplicated health needs may receive a diagnosis and, if required, a prescription without direct interaction with a health professional (Iacobucci, 2017). Such changes in care delivery have been found to be attractive to some patients – typically, technologically sophisticated people without complex care needs – but it requires substantial changes in the ways that care is delivered (Liaw et al, 2019). Two particular causes of concern are the knock-on effects on traditional healthcare organisation, which may be required to manage more people with complex health needs than they have capacity for, and limited validation of the algorithms underpinning patients' interactions and the delivery of diagnoses (The Lancet, 2018). Telecare and digitally enabled models of care delivery enable both professionals and patients to adapt their roles and responsibilities to address contextual needs better, and enable patients to fit health management into their lives more seamlessly (e.g., Schikhof et al, 2010). However, the new experiences, changed relationships, and reliance on technology interaction are not suited to all patients or circumstances.

Even when under the care of a clinical team, many patients or families are largely responsible for their own health management, particularly for long-term conditions. This puts the burden of care on the individual and their family (Mair and May, 2014). Since patients come with variable levels of health literacy, technology literacy and general education, this makes usability a priority since use is typically not discretionary and errors may compromise safety. As noted above, when health technologies are being used outside clinical settings, where there is little immediate access to either technical or health expertise, it is particularly important that people are supported in troubleshooting when anything untoward happens (Rajkomar et al, 2014; Lyons & Blandford, 2018). As Lyons and Blandford (2018) note, even when health technologies are in the home, they are sometimes managed by the care system and professionals, creating ambiguities in the responsibilities of patients, family and professionals. In principle, good design can make the ways responsibilities are shared clearer – e.g., through separate interfaces for different user groups – but I am not aware of any studies of such dual interfaces in home healthcare, other than patient portals to health records (e.g. Osborn et al, 2013).

2.5 Online information resources

While some people access their personal health data, many more access non-personal health information online. People engage in an "information journey" (Blandford and Attfield, 2010) through which they: recognise a need for some information (e.g. due to experiencing health symptoms); seek out information (online, from friends, etc.); validate and interpret that information, in terms of what it means for them; and use the information (e.g., in deciding whether to consult a doctor).

For chronic conditions, it is possible for people to become "expert patients" (Tattersall, 2002) through access to information online and offline, and through education programmes, though when such programmes were first introduced there was resistance from many health professionals, who perceived such patients as overly demanding (Shaw & Baker, 2004). For acute conditions, the availability of online health information makes it possible for people to access information readily, though this depends on the urgency and severity of the condition as well as people's motivations and literacy, including digital and health literacy. In principle, improving information access should improve health literacy, and hence people's ability to manage their own health or to engage in informed discussions with health professionals; in practice, evidence for this is sparse, and problems such as the prevalence of unreliable information online and limited abilities to assess quality or interpret information have been more widely reported (e.g., Diviani et al, 2015).

2.6 Digital Behaviour Change Interventions

As well as supporting people in gaining understanding, another important role for digital technologies has been in facilitating health behaviour change, particularly through mobile apps. Some apps address health issues and others wellbeing. Health issues may be physical (e.g., tracking changes in parameters such as blood glucose for people managing diabetes (Conway et al, 2016)) or mental (e.g., supporting people managing depression, anxiety or addiction (Donker et al, 2013)). Donker et al (2013) argue that although mental health apps have potential to be effective, there is little evidence of the efficacy of many current apps. They propose that this is an issue of public education (in how to identify evidence-based apps). Stawarz et al (2018) reviewed apps claiming to offer cognitive behavioural therapy for depression; they found that apps were used to both replace and augment more conventional therapy. They highlight the importance of privacy, security and trust in contributing to users' experience, and also the importance of engagement (which is assumed to contribute to effectiveness). In terms of development processes, they highlight the need for both evidence-based therapy strategies and evidence-based design approaches. Seeking to address such concerns, Torous et al (2019) propose a set of standards to which future mental health apps should conform, including standards for data safety and privacy; data integration (interoperability) with EHRs; evidence of effectiveness; and user engagement. They note that "the input of clinician and patient end users is often missing when a mental health app is designed, resulting in apps that do not align with the preferences and goals of the intended users", and recommend the application of user-centred design and evaluation in app development.

Based on a survey on attitudes to diabetes apps, Conway et al (2016) report that although people's reported acceptance of mHealth apps was high, their reported engagement with such apps for managing their clinical condition was low. They suggest that "engagement and functionality could be improved by including stakeholders in future development". Broadly, there is widespread recognition that user-centred design is needed, but (as yet) relatively little evidence that this is followed through in practice.

Behaviour change extends from managing health to managing wellbeing, and behaviours that promote a preventative agenda, resonating with the 1948 WHO definition of health as "physical, mental and social well-being". Digital interventions have been developed to help with managing a wide variety of behaviours such as tracking sleep (Ong and Gillespie, 2016); developing mindfulness practices (Laurie and Blandford, 2016); managing diet (Chen et al, 2019); physical exercise (Yang et al, 2015); and stopping smoking (Wu et al, 2016). Some reports on app development include accounts of the behaviour change techniques implemented, or other theory-based rationales for design, and there are a growing number of studies evaluating the user experience of behaviour change apps. However, there are few reports on user-centred approaches to designing such apps in the first place, one notable exception being the person-based approach reported by Yardley et al (2015), which focuses on a psycho-social approach to understanding user needs and practices. However, Yardley et al (2015) do not discuss established user-centred design representations such as personas, scenarios, or design patterns.

2.7 A systems perspective

The number and variety of health technologies and the complexity of the contexts in which they are used pose significant challenges to users. There are well documented cases where patient safety has been compromised by poorly designed user interfaces and systems (e.g., Leveson and Turner, 1993; Cook et al, 2008; Blandford et al, 2014). Whilst specialist clinicians who have in-depth training in the use of specific systems may maintain their skills through successive generations of technology, generalist staff such as ward nurses are typically expected to use a large number of different technologies, with user interfaces that vary from one generation of a product to the next and from one manufacturer to another. There is little evidence of user-centred design in the development of many devices, or of systems thinking – i.e., considering the ecology of technologies that an individual health professional is expected to use in their work, how those technologies interoperate, or how legacy systems are maintained or replaced. Approaches such as SEIPS (Holden et al, 2013) and related human factors approaches (e.g., Carayon et al, 2014) aim to address the design of socio-technical systems, but more attention needs to be paid to usability *in context* – i.e., how a particular user interface can be made appropriately consistent with other interfaces a professional is likely to be familiar with, and how data can be shared sensibly and securely across devices to minimise demands for data entry.

There is a growing recognition that even individual health is complex, particularly when managing multiple health conditions (e.g., Lupton, 2013), and that healthcare systems are most appropriately considered as complex adaptive systems. Van Beurden et al (2011) classify systems into four kinds: simple, complicated, complex and chaotic. A simple domain is well understood; in complicated domains, cause-and-effect relationships are understood, but may be at-a-distance; in complex domains, cause-effect relationships are non-linear and there are many agents with different roles and relationships; and chaotic domains are turbulent and unordered. Glouberman and Zimmerman (2002) note that healthcare systems are often managed and analysed as if they are complicated when in practice they are complex. Greenhalgh et al (2017) have developed a framework to account for the (non-)adoption and spread of digital health interventions, focusing on system complexity as a key factor in this.

Classic HCI techniques, particularly those that involve task analysis or task descriptions, also implicitly assume that systems can be decomposed to simple tasks, which is not the case when the system is complex. Little work in HCI has addressed the question of how to design or evaluate health technologies when viewing healthcare as comprising complex adaptive systems. One exception is the work of Sittig & Singh (2010), who introduce an eight-dimensional model to support reasoning about the design, deployment and evaluation of health IT systems (e.g. electronic health records). Their dimensions are: hardware and software infrastructure; clinical content; the user interface; people such as end-users and developers; workflow and communication; internal organizational features such as policies and cultures; external factors such as regulation; and measurement and monitoring (which implicitly includes learning). These dimensions serve as a checklist, or set of probes, to ensure appropriate coverage of considerations in analyzing the performance of technology within a complex adaptive healthcare system.

Norman and Stappers (2015) introduce the term “DesignX” to refer to user-centred design for complex socio-technical systems, using the example of radiation oncology to illustrate the complexity of many healthcare delivery systems. They highlight nine properties that make designing for complexity challenging, including technical attributes of complex systems such as the non-independence of elements and non-linear causal relationships. They also include the social, political and economic framework within which development and implementation take place, with multiple disciplines and perspectives, and mutually incompatible constraints. Further, they note that system design often fails to take account of human psychology, and that people tend to seek simple answers even when no such answers are available. They note the value and power of observational approaches for understanding the realities of the system context, and argue that designers have a duty to engage with implementation as well as design, and to “develop solutions through small, incremental steps […] to reduce political, social, and cultural disruptions.” In other words, the overall system is not designed; rather, components are designed and the key to overall system effectiveness is in the implementation, which is an ongoing and evolving process of "muddling through" and co-design with relevant stakeholders.

Such an approach may address some of the factors that contribute to the non-adoption of new technologies, but there is also a need to keep sight of the big picture – e.g., in proactively improving work processes, system interoperability and data quality. These themes have not been widely discussed in the HCI literature, and merit more attention if HCI is to have an impact on the usability and utility of health technology, facilitating both care delivery and the use of reliable health data for managing population health (Figure 1).

3. Looking to the future: visions and priorities

In the preceding sections, we have seen that there is significant scope for improvement in the usability, utility, safety and user experience of current health technologies, and in how they fit into the lives of individuals and the workflow of professionals. In this section, I sketch possible visions of the future of interactive health technologies and highlight important roles for HCI in improving those technologies.

3.1 Visions for the future

These sketches are based on narratives that are prevalent in social media and marketing outlets at the time of writing.

There is a utopian vision of digital health that progress will be unrelentingly positive. "Big data" is widely seen as transforming healthcare and medicine (e.g. Raghupathi and Raghupathi, 2014; Cirillo and Valencia, 2019). This vision assumes that people will be willing to share their data (genetic, health conditions, other biomarkers) for limited personal benefit and the greater good, that such data can be combined with socio-economic, environmental and other data to rapidly advance understanding of health and care, and that this will transform care delivery at proportionate costs through the application of novel, interactive and explainable AI algorithms. Patients will be empowered and educated to better understand their own health and care, and behaviour change technologies will support people, at scale, to improve their own wellbeing and manage health conditions. Novel medical technologies – from nanoparticles to large scale scanners, robotics and VR – will make new interventions possible that will work for the good of individuals and populations. People will adopt these new technologies, which will be usable, safe, reliable and effective.

Conversely, there is a dystopian vision that focuses on threats to autonomy and universal healthcare, negatively affecting people's experiences. The same "big data" will compromise people's privacy and security; algorithms will become increasingly opaque and impossible to validate; data will be used for purposes that people did not anticipate; people's confidence in healthcare systems and practitioners will be undermined by breaches in trust; hackers will exploit security vulnerabilities; the rising costs of healthcare, exacerbated by the costs of technology and suitably qualified technical professionals, will limit access, and the problem of differential access to health care ("the digital divide") will grow, particularly affecting those with multiple morbidities or cognitive impairments who are least able to access and use the latest technologies. To manage costs, much care will become transactional, subverting the meaning of the word "care". Technology will become more complex and it will be increasingly difficult to ensure that it is safe and effective. Data gathered using proprietary technology solutions will be owned and used by solution providers for profit. Economic and efficiency objectives will be prioritised over safety and patient experience. The burden of care, particularly for lay carers, will become greater as more responsibilities are devolved from professionals to patients, families and communities, making people feel disempowered and vulnerable.

Predictions of the future are rarely accurate, and neither of these visions is likely to become reality. It is much more likely that there will be a “middle way”, with areas of excellence and areas of poor provision. Some technologies will be adopted, adapted, and found to be valuable in terms of improving patient experience, clinical outcomes and advancing understanding while others will be abandoned as not fit for purpose or will continue to be used despite not delivering benefits. The most successful digital interventions, with greatest penetration and positive impact, are likely to be those with a clinical champion (Ingebrigtsen et al, 2014), addressing a well understood problem.

A key role for HCI professionals (including researchers) in the future is to ensure that issues of safety, usability, utility and user experience are addressed, and that HCI is recognised as an essential component embedded in any digital health development process from the outset. For example, HCI will have an important role in ensuring that future AI systems are “explainable” (Goebel et al, 2018; Holzinger et al, 2017). There is also an urgent need to extend HCI techniques to design for complex adaptive systems. While there is an established (and growing) literature on work system design (e.g. Holden et al., 2013; Carayon et al, 2014) and on the challenges of designing complex adaptive systems (e.g. Greenhalgh et al, 2017), the more detailed questions of how to design interfaces, task structures, etc. for digital technologies that will be components of complex adaptive systems, involving multiple users with different roles and various other interoperating systems, has received little attention to date.

A further issue to address is “pilotitis”: many prototype systems are only deployed and tested for short periods of time because of inadequate consideration of sustainability, or are only deployed within small communities, due to lack of consideration of scaling (Huang et al, 2017). For digital health technologies to make a difference to people’s health and wellbeing, and to have a significant, cost-effective impact, they need to be deployed at scale. As Norman and Stappers (2015) argue, to have a long term effect within complex systems, it is necessary to engage with deployment as well as design. Evaluation issues related to user interactions and effectiveness are illustrated in Figure 4. According to this view, as well as being well engineered (hardware and software perform as intended) and addressing user-centred requirements at different levels of abstraction (being usable, useful, engaging, and fitting the context of use), health technologies also have to deliver clinical benefits by being safe, clinically effective and scalable across care contexts.

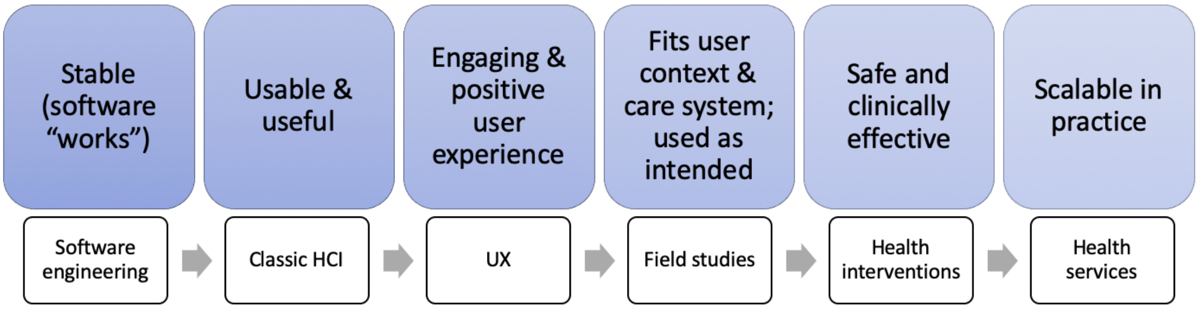

Figure 4: Proximal and distal outcomes: evaluation questions for HCI and other disciplines. Adapted from Blandford (2018)

3.2 Steps in the right direction

While it is tempting to attend to low-hanging fruit, that does not make meaningful progress towards addressing the major challenges in healthcare. Conversely, trying to address the most substantial problems in a single step is likely to lead to failure and frustration, as they appear intractable. The art, as always, is to select problems that are ambitious yet achievable, or where important insights will be gained in the attempt.

One important step is learning to work together: HCI with technology developers and experts in healthcare (professionals and patients) (Pagliari, 2007; Blandford et al, 2018). Another is to tackle problems that cover the entire pathway from user needs to large-scale deployment, considering clinical outcomes, scalability and sustainability as well as more localised issues that are within the "comfort zone" of HCI (Figure 4). Blandford (2018) compares development lifecycles from health systems research and HCI to highlight points of commonality and contrast, but what is needed is a development process that takes the best of both worlds as exemplified in Figure 5. The key features of this are that as well as building on prior evidence, user needs and evaluation (Yardley et al, 2015), this lifecycle incorporates established design representations from HCI (Preece et al, 2015), shows how the design evolves from an early prototype to a deployable mature product, and recognises the need to remain engaged through deployment and diffusion to manage complexity (Norman and Stappers, 2015).

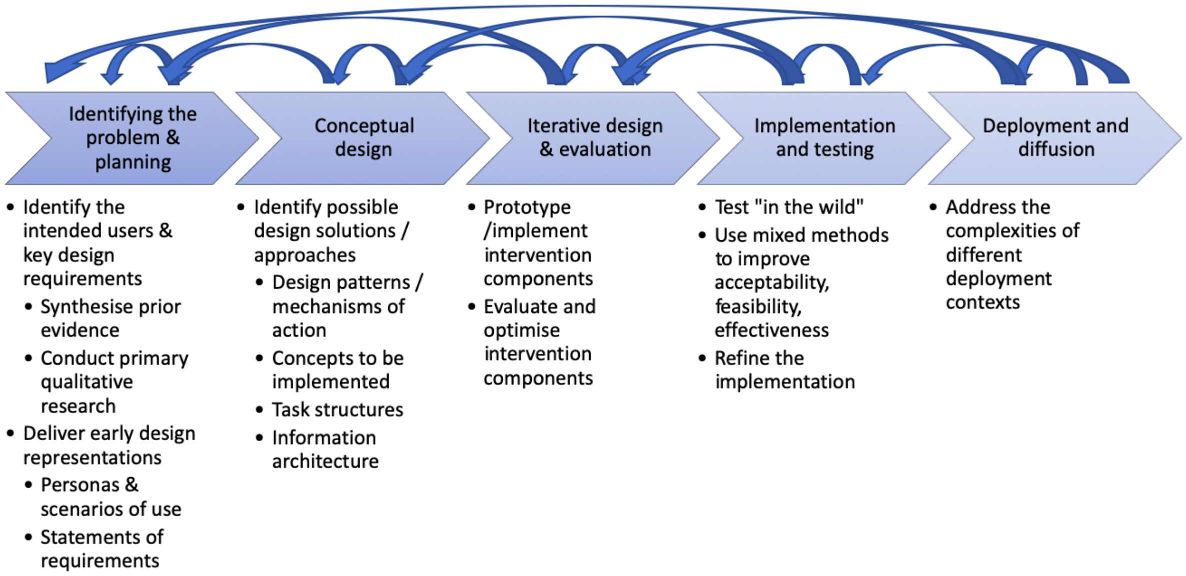

Figure 5: an integrated development lifecycle

As illustrated in the haemodialysis example above, advances in interactive health technologies are often triggered by advances in physical technologies and in understanding of human physiology and psychology for different areas of the care pathway, and user interaction and engagement are afterthoughts (or not explicitly considered at all). Conversely, classic user-centred design does not make reliance on what is technically possible or clinically evidenced explicit. There is a necessary interplay between what is optimal in terms of user experience and clinical outcomes (Figure 4) and what is technically feasible. Often, particularly where the advances are technology-led, it is necessary to focus initially on early adopters within the target community and develop a strategy for diffusion of the innovation; this has rarely been a focus for HCI research.

In summary: HCI has a central role to play if health technologies in the future are to be truly fit for purpose. This will require HCI professionals to engage with the other key players (technologists, health professionals, patients and others) as this is necessarily an interdisciplinary endeavour. It is also important to consider stages (of identifying technical possibilities or early adopters and planning for adoption and diffusion) that are rarely discussed in HCI, but that are necessary to deliver real impact from HCI innovations in healthcare.

3.3 Limitations

Any short paper on a topic as large as digital health interactions will inevitably miss important themes and present a viewpoint that is coloured by the culture and experiences of the author. Given the interconnectedness of themes, this account highlights some connections and downplays others; in particular, it has focused on biomedical and digital systems in the context of health management for physical conditions. It has paid less attention to trends in supporting people in managing mental health issues (e.g. Richards et al, 2016). It has also paid less attention to emotion and bodily experience (e.g., Godbold, 2013), and the social and physical factors that play an important part in the ways in which people engage with their health and experience health technologies. There is a growing body of research in these areas, and an increasing recognition of the importance of considering a broad range of personal and contextual factors in design (e.g., Toscos et al, 2013; Lupton, 2013).

Another area whose importance is becoming increasingly apparent is that of managing multi-morbidities: many health professionals specialise in particular clinical areas, and most interactive medical devices support care pathways for particular conditions. However, people are often managing multiple health conditions in parallel, or managing wellbeing while also dealing with particular conditions. Interactive digital health technologies have the potential to centre on the person, personalising health and wellbeing (e.g., Looije et al, 2010). This might involve an ecology of interoperating tools. However, to date, little research has addressed this area.

As noted, this account has focused on technologies for managing individual health. The value of health data lies in it being used – whether for direct patient benefit, population health benefit, or the benefit of others (insurers, etc.). People's experiences of digital health technologies rely on their confidence in appropriate data privacy (Valdez and Ziefle, 2019), in their safety from hacking (e.g. Dyer, 2017), and in their ability to trust health information (e.g. Sillence et al, 2006); these are areas in which substantial research has already been conducted but more is needed.

This account has focused on Western care systems. Funding mechanisms, care systems, health priorities and access to technology (and other) resources vary from country to country and region to region. These differences shape the ways that digital health interventions are designed, fit into people's lives and are integrated with care systems. The care systems in some low and middle income countries facilitate innovation – e.g., exploiting the prevalence of mobile technologies and a greater emphasis on community-based care, making more agile innovations possible; in other cases, a lack of resources limits where investments can be made. There are many other cultural factors that shape appropriate design and deployment (e.g. Shah and Sengupta, 2018). These are areas in which HCI has the potential to make a substantial difference to health and wellbeing through the design of technologies that are socially and culturally appropriate, as well as addressing health concerns specific to particular regions.

Conclusion

Everyone can expect to need health interventions at some points in their lives. From a user perspective, there are significant challenges in making health technology more fit for purpose and empowering, to health professionals and patients alike. In this paper, I have discussed a variety of digital health technologies, for professionals, patients and analysts, that support health management and discovery. I have highlighted many of the benefits of digital health technologies – from enabling people to live longer, healthier lives to empowering people to better understand and manage their own health and that of others. I have also highlighted areas for incremental improvement, through improved usability, safety and efficiency, and possible transformation of health experiences through new models of digitally enabled care delivery. I have presented models that enable us to map out the "space" of digital health technologies and proposed strategies for engaging with others in this space which is inherently reliant on diverse kinds of expertise and interdisciplinary interactions. Inevitably, with technical innovations (whether novel algorithms or biomedical techniques) will come further interactive health interventions, creating new user experiences.

Healthcare systems are complex, and we need new strategies for designing and deploying interactive health technologies that address the needs and values of their diverse users.

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