Digital health

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Abstract

What can be observed under the notion of digital health? What are the key arguments that shift public and private sector investments towards digital health innovation? And, what kind of theoretical approaches enable us to disentangle the complexities and ambivalences at play when digital technologies are embedded in practices of health and medicine? This chapter provides an overview of the area of digital health, first examining some of the key developments since 1980s and the promissory discourse that often accompanies these developments. It then offers critiques of such promissory discourse at two levels. First, it introduces the social theories that seek to explain the societal consequences of digitalisation and the arising health data economies. Second, it presents the more empirically-driven sociotechnical approaches that have sought to understand the situated character of digital health. Following this, a sociotechnical lens is used to identify three central aspects of digitalisation that are then explored in detail: quantification, connectivity and instantaneity. Using examples from different case studies, an argument is made for how digitalisation is associated with three types of the (re)configuration of healthcare: in knowledge about health and illness, in relationships between patients and healthcare professionals and in new forms of control shifted between technologies and human agents in practices of care. Overall, the chapter aims to provide the reader with important theoretical concepts to approach the study of digital health and its potential benefits and drawbacks across different social situations.

Overview

This chapter provides an up-to-date overview of the current state of knowledge about how digital technologies are embedded within practices of health and illness. This is vast field that has grown exponentially over the last 40 years and is located within and across a range of disciplines (health informatics, sociology, science and technology studies (STS), media studies) that are more or less critical in focus. Any overview must therefore be very selective and clear in its goals. Our own work sits at the boundary of medical sociology and STS (Henwood & Marent, 2019) and explores digital technologies as embedded in practices of health care. This provides the framework for our overview and critique here.

We start by presenting an overview of four broad areas of digital health practice that have emerged since the 1980s – telemedicine, eHealth, mHealth and algorithmic medicine – to give a sense of the heterogeneity now associated with the term ‘digital health’. Second, we reflect on the normative arguments and imaginaries through which digital health has gained momentum as a new phenomenon. In the third section, we offer a brief overview of some key overarching social theories that have sought to explain the growth of the ‘information’, ‘network’ or ‘digital’ society and explore two examples of what are often considered to be important societal level implications of the emergence of digital health.
– the growth of a ‘health data economy’ and threats to ‘health data privacy’. In the final section, we introduce the more empirically-driven sociotechnical approaches to studying digital health, especially those which emphasise the importance of avoiding generalised accounts of the implications of digital health technologies and instead focus on understanding the situated character of digital health, including the specificities of technologies, relationships and embedding environments. We illustrate the value of these approaches through our analysis of three central aspects of digitalisation: quantification, connectivity and instantaneity. Using a sociotechnical lens, we illustrate how these are associated with the (re)configuration of knowledge about health and illness, relationships between patients and healthcare professionals and practices of providing or engaging in care and we highlight the continued ambivalences associated with digital health, across a range of situated practices.

The selection of issues and approaches covered in this chapter is necessarily limited and partial, but our aim is to capture a sense of the current state of the ‘field’ of digital health research that is produced and read by critical social scientists, in particular.

Digital health practices – from telemedicine to algorithmic medicine

In this section, we identify and introduce four broad areas of digital health practice that have emerged since the 1980s – telemedicine, eHealth, mHealth and algorithmic medicine. Although presented as analytically separate and somewhat temporal, they overlap both empirically and temporally and, together, may be understood as constituting the current field of digital health. Here, we aim, simply, to give a sense of the heterogeneity that characterises the field of digital health and of the broad questions and concerns being raised by critical social scientists examining the field. Later sections explore more specific configurations of digital health and the conceptual and social issues they raise.

Telemedicine

In the 1980s, the implementation of personal computers and early videoconferencing technologies converged to enable the emergence of telemedicine, which supported health care at a distance. Early telemedicine applications were designed to enable communication between health professionals to facilitate clinical care in remote communities and/or in the context of rare conditions where specialist input was needed but not locally available (Finch, Mort, Mair, & May, 2008; May, Finch, Mair, & Mort, 2005). Later applications supported remote doctor-patient consultations and even remote monitoring practices – usually of chronically ill people living at home – that have come to be referred to as ‘telecare’. For example, Oudshoorn’s study of telecare in the context of people with heart disease showed how electrocardiogram (ECG) recorders are worn at home by patients to diagnose heart-rhythm irregularities with results being monitored remotely by telecare workers (Oudshoorn, 2012). Telemedicine and telecare might therefore be seen as increasing access to health services for patients living in remote areas and as supporting those living with chronic diseases to have greater autonomy and independence. However, these new practices of remote care also fundamentally reconfigure not only the spaces of care but the nature of care work and the responsibilities for care, having implications for professionals, patients and carers. In teleconsultations, the doctor and patient are no longer in physical proximity and the sensory richness of mutual perception, often experienced in face-to-face consultations, may be significantly reduced. Therefore, telecare involves multifaceted invisible work by professionals and patients with both being required to establish new practices to articulate and
identify symptoms and concerns and to create intimacy and good relationships at distance (Håland & Melby, 2015; Oudshoorn, 2008). Furthermore, these new forms of digitally-mediated care do not simply liberate the patient from the clinic but may actually be experienced as bringing the clinic into the home in ways that may be disrupting or invading patients’ everyday lives (Oudshoorn, 2011; Pols, 2012).

**eHealth**

The introduction of the World Wide Web in the 1990s made health information potentially more accessible for patients and citizens and offered new forums and platforms for sharing health and illness experiences. Health information websites like healthline.com attract many millions of visitors per month and social media sites like Facebook, YouTube or Twitter have become important platforms for people to exchange health experiences. eHealth researchers have investigated how the internet is used to access and share health information and services online. Early research in this area explored the challenges faced by different social groups accessing health information and highlighted the resources and competences that are needed in order to navigate, evaluate and negotiate different sources and types of knowledge and avoid the reproduction of health inequalities via digital inequalities (Wathen, Wyatt, & Harris, 2008). Another related strand of eHealth research examined how the new information landscape, whereby medical knowledge had ‘e-sapped’ from its traditional boundaries (Nettleton, 2004), provided a challenge to medical authority that could lead to the recalibration of traditional doctor-patient relationships and its inherent asymmetries (Hardey, 1999; Kivits, 2009; Ziebland & Wyke, 2012). While health information may well provide a rich source for patients to actively negotiate their treatment, empirical research over many years suggests a wide range of potential possibilities here. Trust has been shown to remain an important factor in determining if, where and how patients access and use health information sourced online and health professionals have also been shown to act, and react, differently to the challenges of the new health information landscape (Renahy, Parizot, & Chauvin, 2008; Stevenson et al., 2019). For example, Stevenson et al. have highlighted how some general practitioners used the internet to check information during consultations while others translated online health information to offer more detailed explanations to patients or signposted them towards resources or self-help outside the consultation. Another strand of eHealth research has drawn attention to the ways in which dominant interests come to shape how health information is portrayed and disseminated by the internet. For example, Lupton (2018a) outlines how search engines like Google can manipulate their software and algorithms to privilege some type of health information over others, especially where companies pay to have their website up-front in search returns. Critical research like this has led scholars to argue that the new information environment raises questions not only about the skills and competencies needed by individuals to become ‘informed patients’ and good neo-liberal citizens, but also about the more critical engagement with the politics of health information needed for the emergence of more active ‘health e-citizens’ (Henwood, Carlin, Guy, Marshall, & Smith, 2010).

**mHealth**

The notion of mHealth is quite recent and signifies health practices that rely on mobile technologies such as sensors and geolocation devices (e.g. Fitbit or Apple Watch), smart textiles and smartphone
applications. These technologies are often worn on the body (mobile), connected to other digital devices and media (interactive) and allow instant access from any location (ubiquitous). By such characteristics these technologies have the potential to monitor bodies, analyse the development of health conditions and promote healthy behaviour, on the move. Personal activity trackers and smartphone apps allow individuals to keep a record of everyday activities (e.g. sleep, physical activities, nutrition intake) and are therefore often seen as facilitating self-care for specific chronic conditions, such as diabetes (e.g. record glucose levels in blood) or HIV care (e.g. record treatment adherence). mHealth technologies have made biomedical data collection easier, leading to arguments that self-tracking is increasingly becoming ordinary and mundane (Pink, Sumartojo, Lupton, & Heyes La Bond, 2017). The often claimed ‘power’ of mHealth relies in the logic of quantification by which fitness targets or health behaviours can be visualised by simple graphs or colours and cross-referenced and benchmarked with peers or population groups. Furthermore, people engaging in self-tracking often aim to discover correlations, for example by comparing their sleep with their running performance. Lupton (2016) has elaborated different modes by which people engage in self-tracking – it can be done as a private activity to enhance self-awareness and improve one’s life, or, communally, with people sharing their data with others on social media in order to experience themselves as part of a community. In many cases, there is a push for self-tracking from external agencies such as governments, employers or insurance companies (see also: Pols, Willems, & Aanesstadt, 2019; Till, 2018) that have an interest in healthier citizens or employees and/or in viewing and using participants’ personal data. Lupton’s (2016) ‘exploited self-tracking’ indicates a mode where personal health data is overtly or covertly collected and commercialised by external agencies such as marketing companies that have an interest in harvesting or selling consumer data.

Algorithmic medicine

Recent advances in computing have seen an increasing capacity for the production, storing and sharing of data – often referred to as the era of ‘big data’ which, in a health context, has led to the claims that we are seeing a ‘datafication of health’ (Ruckenstein & Schüll, 2017). In this environment, algorithms, that have the capacity to filter, sort and process data and automate reasoning, have been regarded as the main drivers that will revolutionise medicine (Obermeyer & Emanuel, 2016). The production and use of big health data sets in the fields such as genomic biobanks (Petersen, 2019, chapter 3) or reproductive medicine (van de Wiel, 2019) require novel technologies such as predictive analytics and machine learning. In the context of reproductive health and embryo selection, van de Wiel (2019) outlined how embryologists’ manual appraisals of embryos ‘in vitro’ are being displaced by a new ‘in silico vision’. This builds on visual information produced through time-lapse embryo imaging and uses algorithmic analysis to correlate data with temporally and spatially disperse embryo cohorts in order to predict embryo viability. What van de Wiel refers to as an ‘algorithmic way of seeing’ has penetrated many areas of healthcare, where algorithms are used to predict and diagnose risks of diseases within individuals or population groups and to select or implement treatment regimens. Other examples are the World Health Organisation’s mhGAP-IG algorithm that has been implemented on a global scale to enable non-specialists to diagnose mental health disorders (Mills & Hilberg, 2019) and an algorithmic-based ‘virtual trainer’, implemented in a physiotherapy context in Denmark (Schwennesen, 2019). These forms of algorithmic medicine may reconfigure the ways in which medical knowledge is produced and social relations are shaped.
The four broad areas of digital health practice we have proffered above are intended to be neither chronological nor necessarily empirically separate from one another – telemedicine and telecare applications are increasing mobile, with ambulatory monitors, internet connections and GPS technologies enabling telecare beyond the confines of the home; health information searching and health community building can just as easily be undertaken on a smartphone while on the move as while sitting at a laptop or desktop in the home or office. Later, we explore some of the more specific configurations of digital health, but first we want to draw attention to another context within which such developments need to be understood – the normative claims and promissory discourses that tend not only to generalise about the likely impact of digital health developments but also help constitute the field of digital health itself.

The promissory discourse of digital health

Great claims have been made about medicine facing its ‘Gutenberg moment’ (Topol, 2015), a revolution driven by the novel digital health practices outlined above. Digital health technologies are widely advocated by policy makers (European_Commission, 2014; Topol, 2019; WHO, 2016) as a solution to the complex challenges facing healthcare systems across the developed countries in the aftermath of the economic crisis (De Vogli, 2011), the aging population (Rechel et al., 2013) and the rise of chronic diseases (Holman, 2005). The ‘sociology of expectations’ literature (Brown & Michael, 2003) provides a useful lens through which to reconstruct the ways in which digital health and new ventures in technology development gain momentum through promissory discourses. In government health and digital policies as well as in associated research and innovation policies, the notions of telemedicine, eHealth, mHealth and algorithmic medicine are often used as part of what Pickersgill (2019) calls ‘performative nominalism’. Pickersgill outlines how the articulation of neologisms, along with the explicit or implicit extolment of specific virtues and expectations, contributes significantly towards the constitution of purportedly novel fields of medical practice that are often vested with interests in expanding professional projects or commercial markets. We argue that ‘digital health’ is a case in point (Henwood & Marent, 2019). Below, we outline two key arguments that are mobilised in support of digital health to encourage and support the utilisation of digital technologies in health care. The utilitarian argument underlines the potential of digital technologies to increase the efficiency, effectiveness and quality of health services, while the empowerment argument highlights the opportunities that digital technologies create for citizens and patients to participate in their own care.

The utilitarian argument

From a utilitarian perspective, digital technologies are seen as a way to increase the efficiency, effectiveness and quality of health services. We can illustrate this through discussion of our EU-funded ‘Research and Innovation’ project, EmERGE (emergeproject.eu), where an mHealth platform for HIV care has been developed, implemented and evaluated across five clinical sites in the EU (Marent, Henwood, Darking, & EmERGE Consortium, 2018a, 2018b). The platform is being implemented as part of ‘reduced visit pathway’ that, it is expected, will increase efficiency for clinics while facilitating greater self-management for patients. The platform offers patients a smartphone application where they can access test results along with messages from clinicians, as well as information about medications
and appointments. This digital care pathway is seen as a more convenient and efficient way for stable HIV patients to receive routine care as it reduces the number of visits to the clinic. Furthermore, by receiving reminders for medication intake and notification for health-related appointments, patients are expected to improve their treatment adherence, thereby increasing the effectiveness of care. For doctors, who analyse and push blood test results, messages and prescriptions (encrypted and without identifiable information) out through a clinical web application to patients’ smartphones, this new pathway is expected to increase efficiency via leaner and more flexible workload allocation, including fewer appointments for stable patients and more time with patients with complex needs.

Many critical digital health scholars have outlined how digital technologies cannot be understood as simple solutions to current health challenges. Sociotechnical approaches, which we will introduce in more detail below, have been adopted to better reveal the heterogeneity and complexity of ‘technologies-in-practice’ (Henwood & Marent, 2019; Lupton, 2018b; Petersen, 2019). In the case of the EmERGE platform, introduced above, the reduction of face-to-face visits embedded within the new care pathway was not experienced by all as quality improvement. Patients, particularly those who were socially isolated, often experienced their face-to-face visits as a meaningful opportunity not just to collect blood test results but to discuss these alongside broader issues such as engaging in intimate relationships or managing emotions (Marent et al., 2018a). Both clinicians and patients may resist the adoption of mHealth applications that, despite being seen as efficient in use of resources, may nevertheless be perceived as a threat towards their understanding of what counts as ‘good care’.

The empowerment argument

The empowerment argument claims that digital technologies provide patients and citizens with personal health data and timely feedback by which they can gain a better understanding of their medical condition and are better placed to manage and participate in their health (Flores, Glusman, Brogaard, Price, & Hood, 2013; Swan, 2012; Topol, 2015). Thus, according to Swan (2012, p. 108), novel digital technologies will lead to a paradigm shift and towards an emancipated patient who is thinking: ‘My health is my responsibility, and I have the tools to manage it.’ Such promissory expectations that emphasise the emergence of informed, activated and connected patients have been deconstructed by critical digital health studies as part of ‘techno-utopian’ discourses that ignore social and political dimensions that are part of how people engage with digital technologies (Lupton, 2013; Petrakaki, Hilberg, & Waring, 2018). For example, such promissory expectations ignore how digital health technologies may act as ‘inscription devices’ (Latour & Woolgar, 1979) that reify medical conditions in a particular way. In the case of the EmERGE mHealth platform, introduced above, specific biomedical measures like viral load and CD4 come to define what constitutes HIV health, while less attention is given to the importance of experiential knowledge and peer-support. While such technologies may increase a particular form of knowledge and place some patients in a better position to negotiate their treatment with healthcare professionals, it also has to be recognised that some population groups, often those with poorer health as well as poorer health and information literacy, will be excluded. In particular, the empowerment argument often ignores the importance of the material resources (e.g. owning a smartphone or other digital device), competencies (e.g. digital literacy) and knowledge (e.g. understanding of medical measures) that are needed to better self-manage one’s health. Therefore, digital health developments may contribute towards further entrenching disadvantages amongst vulnerable groups who are less likely to access and benefit from advances in digital technologies.
In the next section, we introduce key theoretical approaches that challenge promissory discourse, both at the societal level and at the level of practice.

Challenging promissory discourse – ‘societal implications’ and ‘sociotechnical practices’

The promissory discourse of digital health has been challenged at two levels. At the societal level, social theory has focused on the disruptions caused by the increasing use of digital technologies sometimes mirroring promissory discourse, at least in their generalisations and implicit technological determinism. In more empirically-driven theories at the practice level, challenges seek to move away from overarching claims, including the language of promises and threats, to examine situated digital health practices in ways that can offer more nuance regarding the intersection of digital technologies and health care in specific environments.

The societal implications of digital health

In societal level theories, the introduction of new digital technologies has been conceptualised not as a solution to facilitate information exchange or a way to empower individuals but as an evolutionary stage with disruptive societal consequences. Technological innovations in data processing, digital networks and opportunities for instantaneous information exchange have been understood as creating an epochal shift, leaving the modern industrial era behind (Luhmann, 2012) and giving rise to a new ‘network’ society (Castells, 2011) or an ‘information’ age (McLuhan, 1994). These theories have made important contributions to our understanding of how digital data and digital connections, that are increasingly present, come to influence cultural forms and ways of reasoning (Luhmann, 2012), societal power structures (Castells, 2011) and media ecologies (McLuhan, 1994). The increasing ubiquity of digital technologies is considered to have broad societal implications in terms of distributions of power and inequalities, capitalisation of economic interests and the penetration of personal privacy. Such societal level implications can be illustrated by reference to two interrelated aspects of emergence of digital health – the growth of a ‘health data economy’ and threats to ‘health data privacy’.

Health data economy

The heterogeneous practices of tracking physical activities (e.g. via Fitbit), submitting saliva samples for analysis to a personal genome data base (e.g. via 23andMe) or sharing patient experiences online (e.g. via PatientsLikeMe.com), provide digital platforms with potentially huge amounts of data that may be transformed into new kinds of value as platforms sell this data to technology, pharmaceutical, advertising and insurance companies who then use the data to create consumer profiles, calculate cost-benefit analyses or generate predictive health scores, generating further market value. For this reason, van Dijck and Poell (2016) have argued that understanding the operation of digital health platforms involves understanding processes of both ‘datafication’ and ‘commodification’. Furthermore, while digital platforms are based on business models that aim to transform personal data into financial commodities, critical scholars have argued that such business models are often hidden on platform websites by being overlaid by a normative discourse that seeks to persuade people to donate and upload...
their personal data either for personal gain (for example, via personalised and fine-grained overviews of their state of health), or for the good of society at large (by outlining how the resulting ‘big data’ can transform and improve health research, education and care provision for society as a whole) (Lupton, 2014; Sharon, 2018; Van Dijck & Poell, 2016). The ‘public service’ benefit promises are powerfully illustrated by text on the website of the genetic testing platform 23andMe:

‘We are building a powerful, diverse, and ever-growing resource for research that combines advances in genetic analysis with the power of the Internet … So when you send in that DNA sample, you’re not only learning about yourself, you’re joining a community of motivated individuals who can collectively impact research and basic human understanding.’ (23andMe Core Values, quoted and emphases added from van Dijck and Poell 2016)

In their detailed analysis of three different health platforms, van Dijck and Poell have outlined how terms like ‘sharing’, ‘communities’, and ‘partners’ are used to attract and convince people to provide their data. Others have pointed to how, by collecting and uploading their data onto such platforms, individuals engage in ‘digital labour’ that is largely unpaid and invisible in this new health data economy (Lupton, 2018b) and how restrictions on the use of the such data and products is creating a new ‘big data divide’ (Andrejevic, 2014) between large commercial interests who have access to and control over data flows and individual citizens who provide the data in the first place but do not have access. Moreover, platforms such as 23andMe do not provide enough transparency about how data is sold or reused by contracting partners.

Health data privacy

The increased collection and sharing of health data within and across digital platforms has also given rise to discussions about the implications for privacy and security. Recent incidents of data breaches and scandals gave rise to strong public concerns regarding the utilisation of cloud computing and big data in health. In England, for example, the care.data programme was launched by the NHS to collect and store patient data from GPs around the country in a central data base with the aim of improving health services and outcomes (Carter, Graeme, & Dixon-Woods, 2015). The initiative triggered strong public debate regarding data privacy and the involvement of commercial interests. Patients were particularly concerned about the NHS’ ambition to sell its big data sets to commercial entities. These entities were expected to apply data mining methods and data profiling that could create potential for the re-identification of anonymised data. Due to these strong public reactions, the programme had to be abandoned in 2016. Such examples highlight the importance for implementing basic principles of informed consent, data governance and quality and data security to build public trust and transparency regarding the use of health data (Blasimme, Fadda, Schneider, & Vayena, 2018; Jacobs & Popma, 2019). However, these mechanisms become extremely stretched in a digital environment. Informed consent requires informing people about the consequences of providing their data, about data uses and protection measures and about options to erase data. The big data environment challenges informed consent practices as it is difficult to make up-front decisions on possible future uses of data. This requires new procedures that enable case-by-case deliberations alongside the various potential uses of data (Blasimme et al., 2018). By data mining and profiling through the combination of diverse data sets, very detailed and sensitive information about individuals can be revealed (Lupton, 2018b). This requires
increased investments in data protection where innovations in advanced cryptography and blockchain technology could be used to streamline data sharing and traceability and reduce risks of data breaches and misuse (Blasimme et al., 2018).

While these broad and often very general accounts of the societal transformation brought about by digitalisation are important for stimulating thinking and identifying areas for further research, they have been criticised for implying a more or less subtle form of technological determinism – reading off from the functionalities of technologies to the likely social implications.

Sociotechnical approaches to digital health practices

A second and different approach to challenging promissory discourse has been offered by more empirically-driven theories at the practice level. These seek to move beyond universalising claims – whether promises or threats – and examine, instead, situated cases of digital health practices that can offer more nuance regarding the intersection of digital technologies and health care in specific environments.

Scholars working within Science and Technology Studies (STS) have, for many years, pointed out that the ‘social’ cannot be separated or read off from the ‘technical’ and instead have pointed to the mutually constitutive relationship between technology and the social (Bijker, Hughes, Pinch, & Douglas, 1987). From this perspective, technologies have ‘interpretive flexibility’ as they develop and become embedded in different contexts of use with different social groups using technologies in different ways, leading to multiple variations and ongoing reconfigurations of ‘technologies-in-practice’. In more recent, post-humanist, accounts of the sociotechnical, the unit of analysis is the relational and heterogeneous practices that are formed of assemblages of human and non-human actors (see, for example, Actor-Network-Theory (Latour, 2005) and New Materialism (Barad, 2007; Fox & Alldred, 2016)). The emphasis of these theories is on the ‘performativity’ of the sociotechnical assemblages. Below, we illustrate the value of sociotechnical approaches through our analysis of three central aspects of digitalisation: quantification, connectivity and instantaneity. Using a sociotechnical lens, we illustrate how these are associated with the (re)configuration of health care practices in three dimensions – knowledge about health and illness, health care interactions, and new forms of control enabled through instant feedback and alerts. We highlight how such approaches can help avoid universalising claims about digital health developments and highlight the continued ambivalences associated with digital health, across a range of situated practices.

Quantification and the reconfiguration of knowledge

The long-standing debate about digital health and the emergence of a new information and knowledge environment, discussed under ‘eHealth’ above has, in recent years, become much more focused on quantification and the implications of this for how knowledge is configured in specific health practices. An obvious example here is the body of research generated in response to the growth of the Quantified Self movement (Schüll, 2016; Sharon, 2017). Smartphone apps, smart watches, personal activity trackers (e.g. Fitbit) or smart textiles that have inbuilt sensors and geolocation functions that can produce a detailed and, as many argue, ‘objective’ portrait of ourselves. These are powerful technologies because they make data collection as simple and mundane as never before and they use specific visualisation tools to indicate whether intended targets in terms of hours of sleep or walked
steps have been reached (Pink et al. 2017). They also enable users to cross-reference and to benchmark their performance with peers and friends and allow for the discovery of correlations, for example, between sleep patterns and running performance. However, while the functionalities of these ‘self-tracking’ devices are crucial to understanding the new practices that may emerge around them, they do not determine such outcomes in any straightforward way. Sociotechnical accounts, often focusing on user engagement with such devices, have shown that data will often be incomplete – either ‘broken’ and requiring ‘repair work’ (Pink, Ruckenstein, Willim, & Duque, 2018) or simply ‘partial’ as users are often inconsistent in their collection and recording of self-monitoring data (Weiner, Will, Henwood, & Williams, 2020). Quantified data have also been conceptualised as ‘lively’ because they are continuously shifting and recombining their meanings across different assemblages and life situations. Thus, from a sociotechnical lens, we can question the circumstances and relationships in and through which data become insightful or not and what forms of knowledge about ourselves and our bodies are eclipsed by digital data.

In the EmERGE project (introduced earlier) that focused on using digital technologies to self-manage HIV (Marent et al., 2018a), we found that the years since diagnosis with HIV and the relative stability of the HIV condition was central to understanding how users felt about having access to quantified data. In the case of newly diagnosed and unstable HIV conditions, direct access to numbers (before consulting a clinician) was associated with bringing anxiety and uncertainty into care practices because patients were unable to make sense of strong fluctuations of numbers due to their unstable medical conditions. Experienced and stable HIV patients, on the other hand, were confident in reading blood test results and having access to historic overviews of the development of medical parameters was seen as a way to increase knowledge about one’s condition, leaving them feeling more in control of their own condition and care.

Critical scholars have also highlighted how quantified health data are, by necessity, produced through reductive and normative means and may render the understanding of health and the body in specific ways (Lupton, 2018b; Sharon, 2017). In particular, the new obsession with ‘objective’ data has been criticised for undermining people’s awareness for the haptic sensations of their bodies which may lead to a reductionist understanding of the self and its complex health conditions (Maturo & Setiffi, 2016; Rich & Miah, 2016).

Digital connections and shifting relationships

Close face-to-face interactions, where professionals become acquainted with patients and apply their abstract knowledge in concrete ways, have traditionally been considered central to medical practice (Abbott, 1988). Being in each other’s physical proximity, doctors and patients find themselves accessible to their naked senses (Goffman, 1983). The intimacy of the consultation room creates an empirically rich space for experiencing visual body language, human voice, touch and smell which is of central importance to conduct examination and consultation. This interaction order is also constituted through a concurrent time frame, where doctors and patients are simultaneous present and can coordinate their activities through immediate reciprocity. This spatiotemporal ordering of doctor-patient interactions is significantly reconfigured through digital technologies and new forms of mediated interactions involved but the specificities of the technologies, relations and embedding environments are central to understanding these reconfigurations. This can be illustrated by comparing
two different cases: the EmERGE case of HIV care, already introduced, and the case of digitally-mediated diabetes care (Piras and Miele, 2019).

Through the EmERGE platform, digital connectivity was designed as facilitating only asynchronous communication where blood test results are analysed by clinicians and sent direct to patients, together with a reassuring message or, where there were concerns, a request to call the clinic. Clinicians were ambivalent about the loss of synchronicity here. On the one hand, it allowed them for more flexibility and better coordination of their work practices – for example, less interruptions as the need for routine phone calls to deliver results was eliminated. On the other hand, the asynchronous mode on communication embedded in the new platform and care pathway was experienced as restricting opportunities for reciprocity, something patients also mentioned. Clinicians were uncertain whether a message has been received and appropriately understood by patients and patients were frustrated that the app did not allow them to send questions back to clinicians. Both patients and clinicians argued that ‘real’ conversations and immediate reciprocal communicative accounts enabled them much better to gain a feeling of how utterances have been understood. Particularly urgent and complex health issues required immediate reciprocity and patients and clinicians both outlined how they moved from the asynchronous platform to synchronous modes of interactions (like phone calls or face-to-face visits to the clinic) to negotiate and deliberate such issues.

In a contrasting case, a digital health platform created more opportunities to facilitate reciprocity and connections. In their study of digitally-mediated diabetes care, Piras and Miele (2019) found that digital connections can generate new forms of digital intimacy through the continuity of care (in-between clinic visits) and by complementing abstract medical knowledge with exchange of personal messages that allowed clinicians to better understand the life situations and condition of their diabetes patients. This was facilitated by the design of the platform that, unlike the EmERGE case, allowed two-way communication in a rather unstructured form. The remote monitoring in this case was experienced as fostering greater intimacy between patients and care providers and as increasing both the quantity and quality of communication.

Instantaneity and the reconfiguration of control

Digital technologies often confront us with instantaneity and the potential for new real-time relations. Self-tracking devices, for example, can provide immediate feedback during and between exercises and activities, confronting users with their current running pace, and sending alerts about dietary targets or medication reminders. Through notifications on the screen or via sounds and/or vibrations, digital devices can be set to attract the user’s immediate attention that may then lead them to outsource control over the accomplishment of health tasks, such as taking or ordering medications and booking appointments. In the case of the EmERGE app, we found that certain health practices were reconfigured as attentive responses to prompts from the digital device (Marent et al., 2018a). Self-care and health no longer occupied a clearly demarcated space in the temporal structuring of everyday life (e.g. person takes medications as part of a morning routine) but, rather, were accomplished as ‘layered simultaneity’ alongside other social activities. For example, a person is at work while the smartphone app buzzes with a medication reminder, the reminder gains immediate attention and is followed by action, whereby the tablet is taken, and, subsequently, the work is continued. The sociotechnical assemblages formed in such human-technology interactions create ambivalence regarding the question of whether they bring
forth active patients/citizens that take control over their health, or, conversely, create passive patients/citizens that are being controlled by the technical device (Marent et al., 2018a).

In a different case, Lomborg and colleagues (2018), conducting qualitative research with self-trackers in the context of exercise and mood tracking, demonstrated how the instantaneous feedback offered via tracking devices was akin to having a personal coach that takes over the responsibility for monitoring and supports users in accomplishing health tasks and targets. However, as they also observed, users’ attachment to such temporal tracking regimes, especially when combined with overly frequent and negative feedback, could be experienced as a distraction and a source of frustration.

Exploring the temporal flows within sociotechnical assemblages offers a fruitful lens for observing the control and regulating mechanisms that individuals operate on and to which they are subjected. The control projects facilitated through sociotechnical assemblages may come with benefits and risks. They may liberate the individual from the burden of information storage and produce a cognitive agility to exploit opportunities within specific situations (Serres, 2014) but they can also create dependencies, negative experiences and unhealthy practices. In this way, Schwennesen (2019) outlined how algorithmic systems, assisting in conducting physiotherapy, needed to be creatively adjusted and repaired by its users in order to enable a productive relationship between the system and the body exercising and performing therapeutic sessions. In cases where users followed the system too rigidly, they overstrained some muscles and were training too much. Critical to engaging in distributed forms of control in sociotechnical assemblages might be a continuous switch between engagement and disengagement, or, in the words of Michel Foucault (2007, p. 45), a mode of reflexivity that can be simply called ‘the art of not being governed quite so much’.

Conclusion

Digital health is a fast-moving field of research. The current COVID-19 pandemic, in particular, has contributed to a rapid increase in the utilisation of digital health technologies for accessing health information and care providers (Hollander & Carr, 2020). It will be crucial to understand how these new interactional forms between doctors and patients, that are now becoming so widely adopted, may reconfigure roles and relationships and understandings of what constitutes ‘good care’. The sociotechnical approach, outlined in this chapter, offers promising avenues to investigate how new ways of knowing (saturated by quantified data), reciprocity (afforded by digital connections) and temporality (shaped by instantaneous algorithmic calculations) are enacted in digital health practice.

It is also important, however, to recognise that practices are shaping and being shaped by wider material and social structures. This has been illustrated in this chapter by the discussion of the health platform economy, which exploits new business models and market principles for growth and expansion. Platform organisations have developed comprehensive strategies to capture consumer data and commodification mechanisms that help transform almost any ‘behavioural surplus’ (from tracking a run through Fitbit to liking a post on Instagram) into economic value (Zuboff, 2019). The underlying business models and flows of data remain largely opaque and raise significant concerns regarding the public values at stake. How do health platforms and apps protect privacy? How do they contribute to equality in health and treatment? How do they enable informed consent regarding the reuse of citizens’ data? These questions necessitate the development of new governance frameworks that guide the value-centric design of the emerging platform society (Van Dijck, Poell, & de Waal, 2018). Such governance
frameworks need to go beyond the focus on specific digital health devices and address the wider platform ecosystem, because the infrastructure upon which digital health operates is largely owned by a few big technology companies who run search engines (Google), cloud spaces (Amazon), app stores (Apple) and operating systems (Microsoft).

The term ‘digital health’ captures a range of diverse and complex sociotechnical practices and therefore needs to be understood as far more than a set of technological solutions to particular health problems or tools to bring about efficient healthcare provision. Digital health raises critical issues concerning how knowledge, relationships and control are reconfigured in specific use contexts and can inspire social scientists to engage with public stakeholders in both better understanding of these contexts and in co-designing appropriate models and pathways for future care delivery.

References


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