I Theorising Digital Health & Society

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1 Digital Health and Society: A Research Agenda

Abstract: Digital transformation is widely promoted as a solution to healthcare challenges such as ageing populations, chronic diseases and pandemics. This has led to rapid advances in the field of digital health, driven primarily by the computer and health sciences, which are developing devices and interventions. However, digital transformation in healthcare is not always easy to implement. Repeated calls for digital transformation and their technology-centric solutions fail to adequately address issues of implementation, adoption and unintended consequences. What is overlooked is the factor that moderates digital transformation, namely the society in which it takes place. It is important to recognise that society and social practices are not simply passive objects that can be transformed in a linear way. Instead, they are reflexive and responsive to experimentation and intervention. Designing and managing digital transformation in healthcare therefore requires an understanding of society. The *Handbook of Digital Health and Society* brings together leading social science perspectives – from sociology, media studies, STS, psychology, philosophy, political science and more – to explore the complex relationship between technology and society, and to shed light on the conditions under which digital transformation can be successful, ethical and deliver social value. The Handbook thus complements the dominant disciplines in the field of digital health and provides essential guidance for envisioning and developing appropriate and desirable solutions to current healthcare challenges.

Keywords: digital transformation, digital innovation, sociotechnical change, digital health, theory, digital society, digital technologies, health practices, healthcare organisation, managing transformation, digital methods, socio-political challenges, governance

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Introduction

Digital transformation is a widely used term in popular and academic discourse. In most sectors of society, be it business, government or education, transformation is seen as necessary in the face of today's challenges. In healthcare, too, digital technologies are widely advocated as a solution for dealing with limited resources, despite an ageing population, the rise of chronic diseases, and global pandemics. As a result, 'digital health' has become a major area of research, with the dominant disciplines of computer science and medicine developing novel digital health tools and interventions. With a desired effect or outcome in mind, technological artefacts are designed to transform established ways of delivering healthcare.

However, transformation does not always go as smoothly as expected. Repeated calls for digital transformation and their technology-centric solutions fail to adequately address issues of implementation, adoption or unintended consequences. What is overlooked is the factor that moderates digital transformation, namely the society in which it takes place. It is important to recognise that society and social practices are not simply passive objects that can be transformed in a linear way (Nassehi, 2024). Instead, they are reflexive and responsive to experimentation and intervention. Designing and managing digital transformation in healthcare therefore requires an understanding of society.

This Handbook brings together cutting-edge social science research and theoretical insights to shape the field of Digital Health and Society. With contributions from sociology, media studies, science and technology studies, organisation studies, health services research, psychology, philosophy and political science, the Handbook underlines that digital health innovations and interventions are inextricably linked to society. The five sections of the Handbook provide i) conceptual tools for understanding societal change, ii) offer in-depth empirical insights into how contemporary healthcare practices are affected by digital transformation, iii) specify key organisational and managerial insights for improving technology uptake, iv) propose new methodologies for digital health research and innovation, and v) highlight important social and ethical challenges of digital health. The comprehensive understanding of society and the practices specific to different areas of healthcare provided throughout the Handbook shed light on the conditions under which digital transformation can be successful, ethically sound and deliver social value. The Handbook thus makes an important contribution by complementing the dominant disciplines in the field of digital health, such as computer science and medicine, and providing essential guidance for envisioning and developing appropriate and desirable solutions to current challenges in healthcare.

In the following, I introduce the five sections of the Handbook by synthesising and explaining the key themes, concepts and empirical insights developed in each chapter. This provides a comprehensive picture of the digital health research agenda currently developing in the social sciences.

Theorising Digital Health & Society

The *Theorising Digital Health & Society* section of the Handbook brings together important strands of contemporary theory discussed in the social sciences. The chapters in this section show how poststructuralist, new materialist, postphenomenological and systems theoretical approaches provide useful conceptual tools for understanding and engaging with the increasing digitalisation of health in contemporary society. What unites these social science theories is an engagement with their own ontological positioning and an epistemological reflection on how they create knowledge about phenomena. They acknowledge that their theoretical concepts cannot be understood as ‘cameras’ that capture empirical reality, but rather as ‘engines’ that produce it (MacKenzie, 2008). The value of these engines lies in their analytical capacity to see differently, to offer new interpretations, and to engage in the creation of what Donna Haraway (2016, p.76) has called ‘alternative worldings’. This is an essential contribution to the transformation discourse, in which the adoption of new technological possibilities is often dogmatically seen as ‘inevitable’.

The social theories outlined in this section provide an understanding of the relationship between technology and society. Technologies are not neutral tools; they build on and reinforce social assumptions and expectations. For example, care algorithms may be based on gendered or racialised images of who provides emotional labour, or on data that more accurately represents certain population groups and thus provides more efficient treatment to those groups. Social theories also show how innovations in digital health technology fundamentally reconfigure what we can understand ‘the social’ to be – requiring an adaptation of our traditional conceptual toolkit. In doing so, the chapters in this section of the Handbook show how power, agency, perception and communication are changing their modus operandi in the digital society, with significant consequences for individual and population health.

How do digital health technologies exercise power over individuals and populations? An important approach to address this fundamental question can be found in the work of the French philosopher Michel Foucault (1926–1984). Living in the last century, Foucault did not encounter advanced digital technologies such as social media platforms, big data or algorithms. But he was interested in the historical transformation of power, analysing how institutions and technologies are orchestrated to govern “the possible field of action of others” (Foucault, 2000, p.341). Chris Till (chapter 2) draws on two key concepts from Foucault’s theorising, biopolitics and governmentality, to provide a critical lens on the disciplinary and exploitative effects of many widespread digital health technologies. Biopolitics refers to a shift from sovereign power (which seeks to dominate through punitive or violent means) to a form of governance that seeks to control conditions of life and health at the population level. Modern life is shaped by the widespread use of wearables, smartphone apps or GPS and Bluetooth connections, creating unprecedented opportunities for surveillance, commodification and intervention in health practices. Foucault’s concept of governmentality recognises that we use these technologies largely without direct obligation and often internalise the normative ideas inscribed in the technology. By tracking fitness behaviour and sharing and comparing results on health platforms, users are essentially accepting normative ideas about what constitutes good health and an active life. Moreover, the modern entrepreneurial self strives to develop and pursue these goals. Modern government, from a Foucauldian perspective, does not operate primarily through prohibition, repression or domination, but through the careful disposition of things arranged to change practices (see: Lemke, 2021).

But how exactly do things like digital technologies have the capacity to alter bodies, behaviours and thoughts? Do things have agency? These questions arise from a 'turn to matter' that is embraced by a number of contemporary perspectives in the social sciences and humanities, grouped under the label 'new materialism'. New materialist approaches challenge anthropocentrism and bring a new ontology to social theory. Rather than assuming that things are pre-existing, new materialist approaches explore how objects (e.g., digital technologies) and subjects (e.g., patients) come to matter through dynamic 'intra-action', as Karen Barad (2007) would put it through her agential realist approach. This new, relational ontology, argues Nick J. Fox (chapter 3), is needed to study the ongoing cyborgisation of everyday life and must be accompanied by methodological innovation. To advance the new materialist methodology, Fox draws on the 'ethological toolkit' developed by the French philosopher Gilles Deleuze (1925–1995) to study *affects*. Deleuze defines matter as the *capacities* to affect that emerge through interactions within specific *assemblages* of human and nonhuman stuff. *Micropolitics* within these assemblages can lead to ongoing relations of power. Fox uses the ethological toolkit to analyse different cases of digital health, such as a machine learning algorithm to identify genetic design principles for antibodies in automated drug discovery. The micropolitical analysis of this form of drug development and the emergence of proprietary molecules leads to a broader understanding of the workings of digital health capitalism.

A refusal to ontologically separate humans and technologies has also entered phenomenological debates. The postphenomenological departure from its phenomenological tradition stems from the belief that humans and technologies constitute each other through mutual relationships – an assumption shared with posthumanist and new materialist approaches. Moreover, postphenomenologists want to distance themselves from a perceived phobia of technoscientific products that they observe within the phenomenological tradition, which praises authentic being beyond the use of technology. From a more neutral starting point, postphenomenologists examine individuals' relationships with digital health technologies and ask how these relationships transform perceptual experiences of health. Bas de Boer (chapter 4) elaborates the contribution of postphenomenology to digital health along important key concepts. The conceptual pairing of *amplification and reduction* highlights how engagement with digital health technologies magnifies certain aspects of health while neglecting others. The amplification stands out, while the reduction is often overlooked or even forgotten. For example, doctors may focus intensely on the electronic health records on their screens, while the patient's own illness narrative may be sidelined. Postphenomenologists also look at how relationships to technology take shape in relation to an individual's familiarity with it. They use the concepts of *habituation*, which refers to the process of becoming familiar with a particular technology, and *sedimentation*, which refers to the degree to which an individual develops skilled and routine use. Postphenomenological research can also reveal the *multistability* of digital health objects, which do not have a single essence and whose use may not be what their designers intended. To explain this, de Boer refers to the concept of *affordances*, which was introduced by the American psychologist James Gibson (1904–1979) to describe how (human) animals perceive their environment. Rather than assuming a single landscape with defined physical features or objects, different observers perceive selectively, recognising opportunities and constraints for different actions or forms of life. The concept of affordances shows that the possibilities and restrictions of digital health are not built into the technology, but are contingent and emerge from the relationship with particular users in particular circumstances.

The power and capacities that emerge from sociotechnical relations can no longer be attributed to the intentions and motives of human actors alone, and require social theory to move beyond its deep-rooted anthropocentrism. But can emerging technologies such as AI-powered chatbots even join humans in that most challenging of endeavours, communication? This question requires us to rethink what we understand as 'social', and social scientists interested in AI have therefore revisited the systems theory developed by the German sociologist Niklas Luhmann (1927–1998). The notion of system offers a radical relational understanding of communication, which recognises that communication requires at least two conscious participants and cannot be attributed to a single participant. Rather than attempting to reconstruct the inner worlds or motives of human beings, Luhmann (1992, p.251) suggested observing their systemic relationship and acknowledging that "only communication can communicate". Benjamin Marent, Sebastian Merkel, Alan Petersen and Ian Tucker (chapter 5) show that in a passage of his magnum opus, *Theory of Society*, Luhmann cautiously developed the idea that the computer could become involved in the formation of social systems. Luhmann (2012, p.66) argued that advanced computer technology, with its endogenous complexity, could become a functional equivalent of human consciousness – "with unpredictable consequences". Marent et al. draw on interview data with mental health chatbot creators to develop Luhmann's theory and provide a framework for human–machine communication. Their framework helps to explore whether and how we want to live with communicative machines, and how communication can be designed to avoid harm and promote health and well-being.

Digital Technologies & Health Practices

The *Digital Technologies & Health Practices* section of the Handbook explores how health and care practices are evolving alongside technological innovations. Sociologists and cognate social sciences have foregrounded the notion of 'practices' to describe the relationship between humans and technologies as mutually constitutive. On the one hand, a practice lens shows how the development of digital platforms, diagnostic algorithms or care robots has been shaped by social, political and economic forces, and how such technologies, once integrated into social domains, reconfigure practices of seeking health-related information, detecting pathologies or receiving care. On the other hand, technologies – whether platforms, algorithms or robots – acquire their meanings and functionalities through practices of use and have different affordances (opportunities and constraints) for individual users. The chapters in this section provide detailed empirical insights into how searching for health information, diagnosing a patient, conducting a medical consultation, caring for the elderly, engaging in peer support, and even taking medication are practices shaped by emerging health technologies.

Digital media platforms are disrupting the way people engage and participate in all areas of social life – politics, education, consumption, the labour market and certainly health. But how are platforms such as Facebook, Instagram, TikTok, X or Weibo reconfiguring practices of seeking and sharing health information? And with what consequences? Vicari and Ji (chapter 6) provide an in-depth analysis of the *discursive*, *storytelling* and *curation* practices that platforms facilitate. These practices shape information and generate multiple and contested understandings of health and illness. The ubiquity and everyday use of platforms provide a discursive space where underrepresented and 'lay' voices and personal experiences of living with illness can be made visible. The image-based affordances of many platforms facilitate the storytelling of everyday, immediate and emotional encounters with health that can attract widespread attention. However, user attention and content generation are capitalised within the wider corporate platform economy, whose algorithmic recommendation systems curate what content is promoted and what is not. By intersecting with existing social dynamics (e.g., anti-vaccination movements), Vicari and Li show how the logic of the platforms' attention economy provides fertile ground for misinformation, conspiracy theories and disinformation campaigns. Social science research therefore needs to explore how platform specificities (e.g., business models, user demographics, norms, functions and aesthetics) foreground particular conceptualisations of health and illness.

Also in contemporary diagnostic work, perceptions and knowledge of health and the body are being shaped by digital technologies. AI-driven cancer detection, robotic surgery or self-tracking devices require new diagnostic practices that move between senses and sensors. In her inquiry of how digitalisation is reconfiguring diagnosis, Sarah Maslen (chapter 7) challenges utopian as well as dystopian predictions of automation that assume an absolute shift from the body-as-sensed to the body-as-datafied. Drawing on feminist new materialism she shows that innovative technologies do not erase human perceptual capacities but require new skills to sense *with* the technology. The concept of digital-sensory work is developed on the basis of empirical studies that show how psychotherapists have learned to make ‘eye contact’ via the camera to treat their distant patients, how anaesthetists pay dual attention to the monitoring systems and their patient’s body, or how histopathologists, assisted by AI systems, move between the digitally generated slides and the physical sample they see under their microscopes. Outside the clinic, too, diagnosis takes place *with* rather than *by* consumer digital health devices. While these devices purport to take the guesswork out of everyday life and replace subjective experience with objective data, the concept of digital-sensory work reveals how sensing takes place with the ‘more-than-human sensorium’. Empirical studies show how people reason with their data, question technological representations of their health, and experience the feel of activities beyond the data tracked and visualised by their devices. The concept of digital-sensory work sheds light on the diagnostic practices through which clinicians, patients and citizens learn to see, hear and feel with technology.

Care is ‘connective labor’ based on the experience of resonance, of seeing the other and being seen (Pugh, 2024). The face-to-face interaction between the patient and the clinician was therefore widely recognised as medicine’s ‘most powerful tool’ (Timmermans, 2020). Seeing, feeling and hearing the patient in a fully embodied presence allows information to be revealed beyond the verbal content of the consultation and helps to establish a deeper connection. But what happens to care when the clinician–patient encounter is mediated by digital technologies? What might it mean to be present, to respond, to connect and to care in situations that do not allow for embodied proximity? These questions need urgent attention, as telemedicine has expanded significantly since the COVID-19 pandemic. Benjamin Marent (chapter 8) explores the contribution of interactionist sociologists such as Erving Goffman to understanding the particular social dynamics of face-to-face interactions. The interactionist framework helps to observe the changes and implications of digital platform technologies (with video, audio or text interfaces) for the clinician–patient consultation. Rather than overstating the positive outcomes of digital clinician–patient consultations, the chapter introduces key concepts (digital connectivity, invisible work and digital intimacy) to guide the design of remote care and enable reflection on under what circumstances, for which patients, and how different forms of (digital) consultation can provide good care.

Another important line of inquiry is whether and how care could be provided not only by human workers but also by machines. Can robots support or even replace some care work? In health policy, market analysis and media coverage, we can identify sociotechnical imaginaries that present care robots as a panacea for the growing need for care work as the population ages. This techno-utopian vision has been met with concerns from social scientists, who have highlighted that the use of robots could lead to dehumanisation in care work. To understand the ambivalences and multiple implications of robotic care, Benjamin Lipp (chapter 9) develops the framework of human–machine interfacing. This framework elaborates how agency is redistributed between humans and machines and emphasises that care takes place through entangled relationships that simultaneously require care *by*, *for*, and *with* robots. For robots to work, care needs to be operationalised and fragmented into discrete tasks. This reduces the complexity of care to create the kind of narrow tasks that robots can perform. Such care *for* robots also includes efforts to make the care environment ‘robot friendly’, for example by removing everyday objects from an area where robots are working (care *by* robots) so that their sensors are not distracted. Care often involves triadic interactions, where robots are used to assist *with* specific activities, such as lifting an elderly person. Thereby, the robot becomes an object of attention for both the caregiver and the care receiver, and thus an important participant in care practice. The framework of human–robot interfacing challenges the view that care is something that only humans do, or can be done by automated robots, and instead explores how good or bad care is achieved through more-than-human relationships.

The study of more-than-human relationships can also provide insights into how community assets and support are facilitated online. Assets and support do not necessarily come from individual constituent parts of support networks, but from their relational operation. This is illustrated by the findings of Ian Tucker, Katherine Easton and Rebecca Prestwood (chapter 10), who facilitated creative online workshops for people with mental health problems during the COVID-19 pandemic. Participants in these workshops produced writings, drawings and maps through individual and group exercises. The resulting work, often based on powerful visuals, facilitated discussion and enabled reflection on experiences, feelings and attitudes towards the future. The materials and group discussions thus had the potential to reinterpret individual experiences and assets. For example, some participants recognised how they were involved in a web of social connections and felt less isolated, or experienced the joy of creative work and looked to a future in which they could pursue this new interest. Online creative workshops have specific affordances. For participants with certain anxieties, they can offer what Tucker et al. call “forms of minimal presence”, where people can choose to participate without using their webcam and thus may feel less vulnerable or exposed. Nevertheless, some people who participated in online creative workshops felt uncomfortable encountering shared negativity and mental distress. At times when participants were quiet, the lack of response to requests for support felt dispiriting to some participants. The more-than-human approach allows us to trace the relationships through which support can materialise, providing important insights for the design of digital and hybrid community assets in the face of the growing mental health crisis.

Digital technologies not only mediate or automate human work and connections, but they can also act on and through the body, as the recent development of digital pharmaceuticals demonstrates. Jacinthe Flore (chapter 11) discusses the example of Abilify MyCite, a mental health drug (aripiprazole) that incorporates a 1 mm ingestible sensor – called an 'event marker' – connected via Bluetooth® technology to a wearable patch, a smartphone app and a digital web dashboard. The event marker senses ingestion and thus monitors medication adherence. It also detects body movement, recording the individual's steps or rest. This data becomes accessible via the smartphone app or web dashboard, which also suggests mental health exercises such as 'deep breathing' or 'quality time with pets'. Focusing in particular on the workings of the ingestible sensor, Flore argues that this highlights a new form of embodied computing that takes place within the body and requires bodily material (flesh and fluids) to function. When the sensor (made of copper, magnesium and silicon) comes into contact with stomach acid, it activates and sends signals to the wearable patch. These bodily processes highlight a new perspective on the entanglement of humans and technology, where humans do not necessarily interact with the technological device but provide the environment in which it operates.

Organising & Managing Digital Transformation

Organisation studies have emphasised that digital transformation and specific aspects of digital work can be understood as 'sociomaterial' phenomena (Orlikowski, 2007). This term suggests that digital technologies are made operational through practices in which the technical (or, more broadly, the 'material') and the social are entangled. Attention to the entanglement of work and technology enables us to understand how advances in digital health have implications for health professionals' identities, collaborations and power relations. Technological transformation often requires a change in the work culture and attitudes of professionals, which can be perceived as either an opportunity or a threat. New technologies can be seen as an opportunity if they lead to an upskilling of professional work, a gain in status and jurisdiction. Conversely, technologies can also be perceived as a threat to long-established values and practices, leading to ignorance and resistance on the part of professionals. Understanding sociomaterial entanglements can therefore provide important insights for *Organising & Managing Digital Transformation*, as elaborated in this section of the Handbook. The chapters in this section show that organisational and management issues play out at different levels: at the level of individual healthcare organisations, at the level of cross-border infrastructures, at the level of policy and at the level of technology markets.

Digital disruption is often presented in a positive light, as a 'solution' to various challenges faced by healthcare organisations. However, the social science perspectives assembled in this Handbook show that digitalisation is a more complex process that unleashes social dynamics that evolve within the contexts in which technology is used. This insight requires anticipating and assessing both the intended and *unin-*

tended consequences of implementing digital health technologies. Shifting the focus of analysis from the technological solution to the social and organisational context in which it operates can provide important insights into the enablers and barriers to implementation and adoption. Clarity of purpose, trust and organisational support for digital health interventions are important mediators of unintended consequences, as Sue Ziebland and John Powell (chapter 12) show. For example, a lack of perceived purpose or organisational support in implementing digital health interventions can lead to dissatisfaction, increased workload and burnout among healthcare workers. Anticipating these unintended consequences of technologies provides important insights for addressing barriers to implementation (e.g., by engaging change agents, providing training or additional resources) and guiding development and implementation to realise the benefits of digital health.

Examining potential unintended consequences also allows for critical reflection on the outcomes of technological change, such as the rapid adoption of artificial intelligence and machine learning systems that augment or even replace the work of health professionals. Machine learning algorithms can read medical images, assist with triage, predict disease progression or the risk of surgical complications, and analyse speech data to detect early signs of a wide range of conditions – from depression to Parkinson's disease. These systems are often thought to be more efficient and less biased or error-prone than humans. But what are the potential trade-offs for the 'efficiencies' that machine learning seeks to achieve? And what role does human labour play in making these new technologies work? These questions require an ethnographic view from the clinic floor. Chiara Carboni (chapter 13) presents two Dutch case studies of machine learning technologies in acute care: First, the development of a machine learning-powered dashboard in intensive care units that categorises patients as either 'stable' (displayed in green), 'to be monitored orange' (orange) or 'unstable' (red). Second, a pilot of a machine learning algorithm using electronic health records and incident reports to predict patient violence in acute psychiatric clinics. Carboni's research shows a proliferation of additional tasks, with professionals maintaining the technology and adjusting the sensors to ensure reliable data is collected. In addition, professionals were constantly contextualising the data provided by the algorithmic system by listening, feeling and observing their patients' bodies and discussing their observations with colleagues during handover. Carboni thus argues that there is a wealth of knowledge circulating in acute care that is not accessible to algorithmic systems. Carboni also challenges the assumption that machine learning will 'automate' healthcare work. Rather, she sees machine learning as a *labour-redirecting technology* that identifies tasks that can be left unperformed. A patient identified by predictive algorithms as 'stable' or 'non-violent' may not be deemed worthy of a nurse's time and attention. The concept of labour-redirecting technology raises important considerations for policymakers, as machine learning will not necessarily lead to automation, but could lead to the intensification of work, with potential implications for burnout and workforce retention.

Artificial intelligence and machine learning systems require massive amounts of data. Access to local data is not enough; data must be shared and aggregated to create value. Organisational and management issues are therefore not limited to the level of individual hospitals, but increasingly require attention to strengthen collaboration across national borders. Enormous efforts are currently underway, such as the European Health Data Space, to organise data sharing through the creation of cross-border health data infrastructures. In analysing these initiatives to harmonise and integrate data infrastructures, Klaus Hoeyer (chapter 14) points to epistemological and social challenges. In epistemological terms, the further data circulate from where they are produced, the more difficult it is to make sense of them. Hoeyer highlights the differences in local data practices, citing the example of Denmark, where mortality statistics changed radically as more health professionals became involved in writing death certificates by coding schemes. The resulting mortality statistics, Hoeyer argues, did not reflect a change in cause of death so much as a change in coding practices. Knowledge of local data and coding practices and their historical development is therefore important to avoid misinterpretation. Building on the American sociologist Susan Leigh Star (1954–2010), Hoeyer develops an understanding of data infrastructures as sociotechnical achievements. In this view, infrastructures are better understood as activities than objects. Infrastructures do different things depending on who uses them and for what purpose. Analysing the social dynamics surrounding the current creation of cross-border health data infrastructures, Hoeyer reconstructs the agendas and information needs of different stakeholders and suggests that these are unlikely to result in a single entry point to all health data.

The epistemic and social issues (e.g., data accuracy and privacy) emerging from efforts to integrate health data have led to initiatives at the European *policy level* to set standards for medical devices (CE certification) and data protection rules (General Data Protection Regulation). Infrastructuring is also a fruitful concept for understanding the performative role of European Union (EU) policymaking in shaping digital health practices. With the aim of creating a (digital) ‘Health Union’, a mosaic of policy initiatives has emerged over the last two decades to create standards and regulations for medical devices and the data they generate. The European Health Data Space (EHDS, mentioned above) is one product of these policy initiatives. Other examples include the European General Data Protection Regulation (GDPR) and revised CE certification processes for medical devices, including the acknowledgement of ‘software as medical device’. Moving away from a purely technical understanding of infrastructure, Elisa Lievevrouw and Ulrike Felt (chapter 15) reconstruct the social, political and ethical values embedded in the infrastructuring of digital health. Through an analysis of EU health policy documents, they identify a new type of health-related identity, which they term ‘citizen-patient’. Framing Europeans as citizen-patients leads to them being seen as constantly at risk of illness and as an economic factor for strained health systems. This policy framing aims to justify preventive measures and the continuous collection and monitoring of health data. Although health remains largely the responsibility of national member states, EU policy-making efforts have gradually been integrated into national health infrastructures. Through initiatives such as the EHDS or the GDPR, Lievevrouw and Felt argue that it has become impossible for member states to digitise their healthcare systems without adhering to EU standards. Policy documents are thus important instruments that govern "the conduct of the conduct" (Michel Foucault) of individuals as well as corporate actors.

Markets are another important level at which the success or failure of companies and their digital health products is negotiated, leading to the question of how innovation succeeds in the digital therapeutics market. This question is becoming increasingly important as we see digital therapeutics trailblazers withdrawing their services or filing for bankruptcy. Recent and prominent examples include Mindstrong (valued at $160 million) or Pear Therapeutics (valued at $1.6 billion), which provided smartphone applications for evidence-based mental health therapy. Nicole Gross and Susi Geiger (chapter 16) ask why these digital therapeutics companies fail. Drawing on the work of French philosopher Gilbert Simondon (1924–1989), they describe how the innovations of digital therapeutics companies have become a 'technical milieu', detached from human experience, practice and culture. Technologies form a 'milieu' when they are no longer understood and people struggle to integrate them into their activities. This can lead to alienation, creating a sense of fear and hostility towards technological objects. Meaningful innovation therefore requires the successful interweaving of sociomaterial assemblages that include novel technical objects, human beings and the natural environment. To overcome technological alienation, companies need to give more power to key stakeholders – their needs, desires and realities – in the creation of technologies. This includes qualifying their offerings by being transparent about the creation, operation and evidence on which their technology is based. Transparency also includes the modes of exchange, where companies need to develop much higher standards of economic value sharing than today's techniques of extracting value from the assetisation of customers' personal and media data. Only by aligning technological and market innovation with social practices and cultures can digital therapeutic companies make a sustainable contribution to mental health care.

Methods for Digital Health Research and Innovation

As outlined above, sections i–iii of the Handbook look at the digital as a sociomaterial phenomenon, with social research being conducted to understand how digital technologies and data-intensive practices are changing the way healthcare is delivered. However, digital technologies and data practices also require and enable new ways of doing research. Section iv of the Handbook therefore asks whether we need new ways of conducting empirical research and innovation in healthcare. According to science and technology studies scholar Richard A. Rogers (2009), the digital both requires the digitisation of social research methods and leads to the development of ‘natively’ digital methods. This distinction is also present in the chapters of this section of the Handbook. Following the first approach, some chapters seek to adapt established methods such as ethnography or co-design practices to the digital realm. Other chapters show how new research methods are being developed to take advantage of new data-driven approaches in biomedical research or to study digital artefacts such as smartphone applications. While social media and data-intensive practices have led some to advocate for positivist and computational approaches in social research and health sciences, the chapters in this Handbook draw predominantly on qualitative modes of inquiry to understand the multiple meanings and emotional dimensions of engagement with digital health technologies, to uncover the norms and assumptions reflected in technologies, or the political and economic interests behind their use. Rather than allowing data to drive knowledge generation, they raise key issues of data-driven biomedical research, such as informed consent or value creation. The chapters make us aware of the new research possibilities of digital devices and practices, but also remain critical of the ways in which data is captured and socio-cultural norms are inscribed in digital devices. In doing so, the chapters follow science and technology studies scholar Noortje Marres’ call to design research and methodology both “*with and against* the digital” (Marres, 2017, p.114, italics in the original). The specific methodologies applied to digital health research and innovation in this section of the Handbook, as outlined below, include ethnography, creative methods, feature analysis, co-design and data-driven approaches.

In the first chapter of this section (chapter 17 of the Handbook), Giada Danesi introduces ethnography as an approach to the study of cultures from the perspective of individuals. Ethnography is thereby largely based on observing practices in specific settings to document patterns of interaction and reconstruct local meanings and perspectives. But how can this approach be applied to digital health environments, where practices are not always directly accessible to the ethnographer’s gaze, but mediated by technology? What are the challenges of a digital ethnography, and what can ethnography contribute to understanding digital health practices? Giada Danesi shows that ethnographic research on digital health has focused on two phenomena. First, the study of practices of searching for and sharing health-related information on the web. And second, a close examination of the design and use of digital health technologies and data-intensive care practices. In studying these two phenomena, ethnography extends technology-centred research to explore the intersection of online and offline worlds, to reveal the multiple uses and contested meanings of technology, and to engage with non-users of technology. Danesi demonstrates this contribution of ethnography through her research on a dietary app. In her project, she followed users on their daily shopping journeys and explored their different habits of monitoring and evaluating dietaries. Danesi also engaged with people who were reluctant to engage with dietary apps. She argues that by engaging with non-users and vulnerable groups who may not have access to digital health devices, ethnographers can engage with voices that are often excluded in technology development. In doing so, ethnography can uncover important barriers to digital health adoption and explore design alternatives to address emerging digital health inequalities.

Health is a resource for living that builds relationships between humans and the more-than-human environment they inhabit. Flourishing and failure to thrive results from a dynamic relationship between humans and non-humans. Deborah Lupton (chapter 18) brings more-than-human philosophies into methodological considerations to advance creative approaches to digital health research. Creative methods can provide insights into the 'non-representational' dimensions of health and human experience. They reveal the multi-sensory and affective dimensions of health and illness that are difficult to capture through traditional methods such as direct questioning or observation. Lupton shows how creative methods provoke thought and broaden people's perspectives on their relationships with other living things, places, connections and technologies as part of their health and well-being. Through her research projects Lupton provides examples of how workshops can be used to create concept maps of the complex health information ecologies that people navigate in their everyday lives. Creative methods can also facilitate future-focused workshops, such as developing graphic fiction storyboards where people imagine 'A Day in the Life of a Care Robot'. To bring this extensive research to the public, Lupton also writes about her experience of curating an exhibition and working with a filmmaker and artists to create works for display that expand thinking about bodies and health in relation to a much wider ecosystem of agents, as captured in the increasingly important concept of One Health.

An important social science insight, which is emphasised throughout the chapters of this Handbook, is that technologies are not neutral or apolitical. Rather, technology design reflects human values and politics, reinforcing existing assumptions, norms and inequalities. Smartphone apps therefore need to be understood as 'sociocultural artefacts' (Lupton, 2014) that are created around a defined set of problems and solutions. Amy A. Hasinoff and Reana Bivens (chapter 19) develop a method they call 'feature analysis' to enable researchers to analyse how social norms and assumptions are manifested in a large set of apps. They demonstrate the application of feature analysis in four successive phases. Their interest is based on the study of apps that claim to prevent rape. Hasinoff and Bivens show how feature analysis is conducted by detailing their search for apps (phase one), identifying and documenting app features (phase two), analysing how the features define a problem-solution package (phase three), and finally using speculative design to imagine alternative framings or features (phase four). Feature analysis is based on non-reactive data sources (apps) that reflect the actual choices made by developers within their financial, technological and regulatory constraints. In doing so, feature analysis provides an opportunity to reconstruct the social norms and assumptions manifested in a set of apps.

Many chapters in this Handbook demonstrate how digital health developments are imbued with normative assumptions about how things should be or visions of desirable futures. Co-design initiatives have been important in incorporating more pluralistic values into design artefacts. However, in reviewing the historical development of co-design practices, Joseph Donia and James A. Shaw (chapter 20) highlight three shortcomings of co-design that have undermined its potential to address the key challenges of the contemporary digital health field. First, design practices are criticised for being anthropocentric and therefore primarily concerned with human participation, rights and representation. The individual-centred solutions that emerge from these forms of co-design have failed to address global inequities, the political economy of data governance, or broader social harms. Second, design practices focus on the datafication of healthcare, taking for granted the power of data to represent health and illness in productive ways and seeking to extract financial value from data. Third, the focus on co-design has assumed that the agency to shape artefacts and their meanings rests with the people involved in the design. What has been largely neglected is the power of widely held norms, standards and other objects that shape healthcare practice. Donia and Shaw show how a shift in the normative direction of co-design could address these key challenges of digital health. They propose a posthumanist orientation to co-design that includes objects and extends the conceptualisation of agency beyond the human designer. A posthumanist framework also broadens the understanding of 'innovation' to include the wider social, environmental and political-economic implications of product development.

In the final chapter of this section (chapter 21), Richard Milne introduces data-driven approaches that place large, complex and multimodal datasets at the centre of scientific inquiry. Milne traces the historical development of data-driven biomedical research from the Human Genome Project in the 1990s to a current estimate of 187 genomic initiatives (50% in the US) that have fully sequenced the genomes of 38 million individuals. To provide the computing power and machine learning models needed to analyse the data, research institutes and public healthcare providers have formed often controversial alliances with technology companies such as Google, Amazon and Nvidia. Key issues raised by data-driven research and the alliances it has created are those of informed consent, value creation, and sharing and access to biomedical data. Data-driven research therefore requires new considerations of informed consent, as storage and mobility capacities have led to 'immortalised data' with unclear boundaries of when research begins and ends, and unclear risks of re-identification of data and thus privacy. The creation of data as informatic commodities, largely decoupled from their biological sources, needs an understanding of how data become valuable and who extracts that value. These questions often reveal discrepancies between the embodied labour of data production by clinicians, patients or citizens, and the extraction by those who own, distribute and sell these data. The commercialisation of bio-resources by private companies often leads to reduced data mobility, undermining efforts to make research data widely accessible and shareable for public research organisations. What is needed are new governance frameworks and models for greater data solidarity, which are discussed in section V of this Handbook.

Socio-Political Challenges & the Governance of Digital Health

The first four sections of this Handbook provide us with *theories* (i) and *methods* (iv) to *manage* (iii) and investigate digital health *practices* (ii). The social research approaches assembled in this Handbook show that digital transformation in healthcare and beyond implies societal change. This requires attention not only to the potential positive outcomes, but also to the challenges of digital transformation for society and the political-economic structures of the digital ecosystem. The final section V of the Handbook therefore addresses the *Socio-Political Challenges & Governance of Digital Health*. The chapters in this section describe how digital health technologies can increase health inequalities and feelings of isolation or loneliness among individuals, and create new expectations and responsibilities for citizens to participate in health and care. Looking at the asymmetries in the political economy between the Global North and South, the chapters also ask if and how health platforms can contribute to new forms of colonialism. This line of research leads to new attempts at governance and the development of frameworks that should lead to new forms of data solidarity and anticipatory and value-based approaches that prioritise the well-being of all members of society.

The first question that this section addresses is: Why do inequities in health persist – or even increase – with the spread of digital health technologies? The health gap, argues the epidemiologist Michael Marmot (2015), cannot be explained in terms of individual behaviour. Rather, it results from social determinants such as poverty, discrimination or unequal access to education. Trisha Greenhalgh, Tiffany Veinot and Laiba Husain (chapter 22), follow this line of argument to provide an understanding of the emerging digital health disparities. On the one hand, social structures are built into technologies, and Greenhalgh et al. show how intersectionality theory can reveal the multiple and interlocking systems of oppression inscribed in supposedly ‘neutral’ or ‘objective’ technological tools and algorithms. On the other hand, social structures shape individual practices and their capacity to engage with digital technologies. For this second line of argument Greenhalgh et al. draw on the French sociologist Pierre Bourdieu (1930–2002). Bourdieu emphasised that how individuals think, feel and act is not simply a rational choice, but the result of social factors that culminate in a particular habitus. Habitus and individuals’ access to different forms of capital – economic, social, cultural, and digital – can provide an important understanding of how individuals may or may not engage with digital health interventions. Greenhalgh et al. therefore call for more theory-informed digital health interventions to address structural inequities and overcome the widening health inequalities. They show how the use of user personas and co-design practices can ensure that technologies become more inclusive.

Another important line of inquiry into the socio-political dimension of digital health concerns the relationship between technology and loneliness. Loneliness is defined as the negative feelings that result from a lack of interpersonal relationships. Humans are seen as social beings, and a lack of communicative encounters with others is often presented as pathological and stigmatised. Alan Petersen and Barbara Barbosa Neves (chapter 23) highlight how the dominant framing of loneliness as an 'epidemic' has underpinned a new market for digital technologies. Social media platforms or AI chatbot companions are often seen as a way to provide new connections and prevent the health risks of loneliness, whose impact on mortality is reported to be similar to smoking (up to 15 cigarettes per day), obesity and physical inactivity. Drawing on the perspectives of sociologists of emotions and historians, they develop a critical perspective on loneliness that sees technology not only as a 'solution' to, but also as the soil of contemporary emotional life and social isolation. They suggest that a sociological approach is needed to critically assess the implications of recent advances in affective computing and humanoids, and the sociotechnical construction of emotional experience and expression.

How does the digitalisation of healthcare affect the role of citizens? What are the rights, expectations and responsibilities of citizens or patients in the face of new digital health technologies? Social scientists address these questions through the concept of digital health citizenship. From the early days of telemedicine in the 1970s, through the rise of the internet in the 2000s, to the current uptake of wearables and mobile devices, there has been a vision that digital health will empower citizens and patients to participate more actively in their care. Digital citizenship has been seen as a right to participate in society through online means, and policymakers have been concerned with bridging the digital divide. Henriette Langstrup (chapter 24) describes governments' efforts to provide digital health tools and services to their citizens as forms of 'invited participation'. Drawing on her studies of digital Patient Reported Outcome Measures (PROMs) and algorithmic rehabilitation after hip replacement, Langstrup highlights the new expectations for citizens to actively engage in their own care, but also to generate and share data that should benefit wider societal ambitions to create a data-driven healthcare system. However, these top-down initiatives characterise one end of the participatory spectrum of digital health citizenship. At the other end, Langstrup locates the often 'uninvited', collective and activist mobilisation of digital health devices. One example is the #wearenotwaiting movement, an online community of people with type 1 diabetes who have peer-produced algorithmic pancreas systems in critique of and outside of approved diabetic self-care devices. Digital health citizenship is thereby practised not by using prescribed medical devices, but by challenging the tools provided by the tech industry, healthcare systems and regulators. By sharing data and experiences to further develop devices, collectives such as #wearenotwaiting are using digital opportunities to improve care for themselves. Such activist practices at the margins of established care infrastructures can explore visions of desirable care futures.

Looking at the asymmetries in the political economy between the Global North and South, Dimitra Petrakaki (chapter 25) draws the attention to the relations of power and control that are deeply embedded in contemporary platforms. The capture, extraction and appropriation of data by large platform companies has been identified as a modern form of colonialism (Couldry and Mejias, 2019). Developing this critical perspective in a novel direction, Petrakaki explores the colonising effects of health platforms in the Global South. Her study includes two UK-based platforms that aim to provide online clinical training and transfer of surgical skills through virtual reality in post-conflict and low middle-income countries in Africa, and a Singapore-based platform that aims to educate patients and caregivers in East Asia. Petrakaki draws on Michel Foucault's conceptualisation of the relationship between power and knowledge to develop the notion of 'epistemic colonialism'. For Foucault, knowledge is never neutral or objective but is always shaped by power relations and in turn reinforces and legitimises power structures. Petrakaki identifies forms of epistemic colonialism in the platforms she studied, as they 1) often convey knowledge in a language (mostly English) other than the native language of the users; 2) often neglect local traditions, customs or beliefs; and 3) transfer knowledge that relies on the use of equipment or infrastructure that is not available in the recipient country. Petrakaki argues that epistemic colonialism risks transforming local recipients into Westernised surgeons or patients, alienating them from their local realities or communities.

Critical examination of colonial structures reveals that the benefits and risks of digital health data use are not equitably distributed. Large corporate actors in the Global North make enormous profits from digital practices in the Global South. The reason for this inequity lies in the political economy, which is characterised by asymmetries of power and resources, supported by laws and policies. Connor Hogan, Barbara Prainsack and Seliem El-Sayed (chapter 26) develop a theory-based framework for assessing the public value of data use in healthcare and beyond. They emphasise that public value is a collective good that is realised under certain conditions. First, when data contribute to widely agreed goals in society; second, when no individual or group is likely to be at risk; third, when procedures are in place to mitigate harm; fourth, when the process of data use is publicly transparent; and finally, when it is motivated by an intention to benefit society. Hogan et al.'s framework recognises that simply giving individuals more control over their data does not address broader political-economic structures. By emphasising the need for data solidarity, the framework aims to strengthen collective forms of responsibility and control, and to ensure that data use contributes to the common good.

Earlier in this introduction, it was highlighted that the title of the Handbook, Digital Health and Society, recognises that digital transformation in health and beyond requires an understanding of society as the foundation upon which any transformation effort must be built. The chapters in the Handbook therefore go beyond a narrow technical definition of 'digital health' to show how digital transformation is changing our understanding and expectations of health and what it means to live well. In the final chapter (27), Louise Holly and Ilona Kickbusch ask how digital transformation can be governed for health and well-being. Building on their work as policy and research advisor (Holly) and co-chair (Kickbusch) of the joint *Lancet and Financial Times Commission on governing health futures 2030* (Kickbusch et al., 2021), they argue that improving health in a digital society is not just about digitising health systems, but also about cultivating online and offline environments that promote health and well-being for all. Digital health governance therefore requires attention to the digital determinants of health. These determinants include the provision of digital health services and interventions, but also require attention to the positive or negative impacts of digital transformation on society (e.g., climate and natural environment, education, work, etc.) and the political-economic structures of the digital ecosystem that influence the inequitable distribution of access, risks or benefits of participation in the digital society. Holly and Kickbusch outline how digital governance and health governance need to become aligned and based on anticipatory, precautionary and value-based approaches to pave the way for a digitally empowered society that prioritises the well-being of all its members, both online and offline.

Conclusion

The theories, methods and empirical evidence provided by the social scientists in this Handbook show that digital health is not just a simple solution to improve the quality, efficiency and effectiveness of healthcare, or a way to empower individual patients. What is often seen as a simple technological intervention encounters social or societal dynamics that unfold with disruptive and often unintended consequences. Throughout its twenty-seven chapters, the Handbook demonstrates how digital transformation requires health and medical practices to address and harness the combined and interrelated challenges of increasing quantification (e.g., data-intensive medicine), ubiquitous connectivity (e.g., telemedicine), and unprecedented forms of autonomous computation (e.g., mental health chatbots or medical machine learning). This social science-based understanding highlights that digital health is as much a social phenomenon as a technological one, with significant opportunities but also risks if the social and ethical dimensions of innovation are neglected. There are three critical lines of inquiry into the digital transformation of healthcare that are developed throughout this Handbook.

(1) The proliferation of quantified data and the question of (non-)knowledge
(2) The ubiquitous forms of connectivity and the question of social relations
(3) The unprecedented modes of autonomous computation and the question of agency

In what follows, each of these critical lines of inquiry is elaborated, indicating what it contributes to social science analyses of digital health and how work along these lines can be developed.

(1) The proliferation of quantified data and the question of (non-)knowledge

Quantification is not a new phenomenon, but it is expanding rapidly with social media, wearable sensors and mobile devices, and advances in data-driven medicine and biomedical research. These technologies capture health behaviours and bodily markers and translate them into metric – or quantified – forms and representations that enable analysis and comparison. Approaching quantification as a sociotechnical phenomenon recognises the inseparability of technology and knowledge. What we know is inextricably linked to how we know, how we produce knowledge. And any form of knowledge production has its blind spots. Knowledge generation includes exclusion or ignorance. The social science approaches to quantification collected in this Handbook therefore pay attention to the politics of health data production. How physical conditions and health behaviours are recorded and measured is the result of social struggles and the assertion of powerful interests. The chapters in this Handbook show that only some parts of the empirical world are subject to datafication, and that a wealth of knowledge circulates in clinics and other sites of health practice that is inaccessible to technological systems. The data captured and produced by digital health devices amplify certain aspects of health while neglecting others, producing knowledge and non-knowledge, certainty and uncertainty. Rather than an absolute shift to ‘quantified health’, Sarah Maslen (chapter 7) argues that health professionals are learning to sense *with* technologies, as they move between the body-as-datafied and the body-as-sensed. Beyond an analysis of how supposedly objective data is produced, the Handbook looks at the wider societal consequences of quantification. It shows how data is distributed and commodified by powerful corporations, and considers new forms of governance that lead to greater data solidarity and strengthen collective forms of responsibility and control.

(2) The ubiquitous forms of connectivity and the question of social relations

A second critical line of inquiry developed in this Handbook explores the ubiquitous forms of connectivity that are facilitated by digital networks. The chapters in the Handbook challenge solutionist assumptions that see digital technologies as simple tools to make collaboration and interaction between healthcare providers, patients and citizens more efficient. Instead, they show how digital technologies embedded in health practices are reconfiguring social relations and thus the basis on which health and care are produced. New ways of interacting on social media sites, messaging apps and video conferencing software have led to significant changes in how care is facilitated and sustained as ‘connective labor’ (Pugh, 2024). The contributions in this Handbook therefore explore what it means to share personal experiences of illness, to engage in peer support and to provide care through digital technologies. They show that social media can create exciting sites for sharing personal experiences of living with illness and for facilitating support. However, platform specificities can also lead to specific conceptions of health and illness and increase the spread of misinformation. People seeking help may be exposed to discouraging images of health or negative feelings. Social media platforms and other emerging technologies, such as chatbot companions, are often seen as providing new connections and preventing loneliness. However, the social science approaches collected in this Handbook also explore the wider impact of social media sites and affective computing on emotional life, asking whether they may provide a breeding ground for social isolation and loneliness. Rather than overstating the positive outcomes of digital connectivity, the Handbook provides conceptual advances to guide the design of remote care practices. In doing so, it aims to stimulate reflection about under what circumstances, for which people, and how online connections can facilitate support and good care at a distance.

(3) The unprecedented modes of autonomous computation and the question of agency

A third critical line of inquiry developed in the Handbook looks at how advances in computing power and artificial intelligence are contributing to a wide range of capabilities that enable new forms of automation, taking over some of the tasks previously performed by human professionals. Trained on large data sets, machine learning algorithms can become diagnostic, therapeutic or caring agents. They assist humans in challenging tasks such as decision-making, communication or connective work. In doing so, AI-driven algorithms challenge the notion of agency as a human-anchored phenomenon. The Handbook develops approaches to understanding the implications of automation, artificial communication and post-social interactions that become part of health practices. These approaches do not follow the laudatory tones of popular discourses on what new forms of generative AI systems can do. Such discourses often follow a substantialist account of agency, where agency is seen as an intrinsic capacity of AI systems to produce autonomous and human-like outcomes. In contrast, the Handbook offers a relational conception in which agency is not an attribute of either humans or non-human technologies, but the product of their ongoing intra-action (Barad, 2007). This conceptualisation allows for a detailed analysis of the processes through which AI systems are implemented in care practices, recognising the hybridity and dispersion of agency within sociotechnical relations. Thereby, agency is not seen as a single stable entity, but as part of an ensemble of people and technologies that make up AI systems in particular contexts. Investigating the implementation of AI in specific social and organisational contexts provides a more detailed understanding of the opportunities and the potential negative consequences of automation and algorithmic control in healthcare.

By providing an in-depth overview of the contribution of the social sciences to the growing field of digital health, the Handbook aims to serve as an important reference point for academic researchers, professionals and stakeholders in the health sector, as well as for new teaching programmes on digital health that have been established in universities in recent years. As a reference point for these actors, it aims to enable reflection on the social dimension of innovation as a basis for a research agenda to shape desirable futures for health.

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