

# Towards critical digital health studies: Reflections on two decades of research in *health* and the way forward

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## Abstract

In this article, I provide some reflections on critical digital health research in the context of *Health's* 20th anniversary. I begin by outlining the various iterations of digital technologies that have occurred since the early 1990s – from Web 1.0 to Web 2.0 to Web 3.0. I then review the research that has been published on the topic of digital health in this journal over the past two decades and make some suggestions for the types of directions and theoretical perspectives that further sociocultural and political research could tackle. My concluding comments identify four main areas for further research: (1) devices and software, (2) data materialisations, (3) data practices and (4) data mobilities.

## Keywords

illness behaviour, patient–physician relationship, technology in healthcare, theory

## Introduction

I was one of the founding co-editors of *Health*. In the initial editorial written by the founding editor, Alan Radley, and the other co-editor, Christian Ritter, to establish our vision for this new journal (the brainchild of Radley), we noted the importance of publishing research in the journal that addressed aspects such as medical technologies, consumer cultures and the mass media (Radley et al., 1997). What we could not have known at the time of writing was the ways in which these aspects of health and medicine would converge in later years in the form of digital health technologies. Two years later, in a

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second editorial I penned for a special issue for *Health* on health, illness and the media (Lupton, 1999), I highlighted the importance of recognising the ways in which lay people learn about health, illness, disease and medical care from the mass media. In a third *Health* editorial (Radley et al., 2006), this time outlining reflections on the first decade of the journal on the part of Radley, Ritter and new co-editor Julianne Cheek (who had replaced me after I stepped down as co-editor), the growing influence of the Internet was remarked upon. In the 8 years between the publication of my special issue on media and health and the first decade anniversary editorial, websites and blogs on health and medical topics had proliferated. Lay people were no longer confined to accessing news reports, documentaries and dramas on the one-way legacy media channels (television, cinema, print media and radio). In response, *Health* authors had begun to research the new digital media phenomenon and the ways in which patients and others were seeking information and exchanging experiences of medical conditions, healthcare and caregiving online.

Another decade on, and the present special issue involves a further set of reflections on the first 20 years of *Health*. Over this time, the digital health technology landscape has transformed radically. The expansion of the Internet and the World Wide Web, the introduction of social media platforms and the emergence of mobile wireless computing, sensor-embedded technologies and wearable devices have resulted in new forms of information about and representations of human bodies, health and medicine being generated and circulated. I have elsewhere (Lupton, 2014a, 2014b) called for the development of a field of study that I entitle ‘critical digital health studies’ which sets out to research and theorise these complex entities, their meanings and their impact on concepts of human embodiment, subjectivity, social relations and social institutions. This article represents a further contribution to the development of critical digital health studies. I comment on the investigations about digital health that have been published thus far in *Health*, make some observations about the research hiatuses I perceive and outline directions for further research.

## **Digital health research in *Health***

Social scientists have been researching digital health technologies ever since the Web 1.0 era began to generate a multitude of websites discussing health and medical issues. Web 1.0 is usually dated from 1994, when the Internet became readily accessible to the public’s use via commercial web browser providers able to offer access to the World Wide Web. The production of dedicated websites enabled health and medical workers and authorities to develop websites to convey information to the lay public. Patients began writing their own blogs and developing interactive forums (listservs, discussion groups and message boards) to connect with each other and share information. These were largely closed groups and networks (‘intra-social’ networks), not available to outsiders for access or comment. The emergence of Web 2.0 (or the ‘social web’) is usually dated from around a decade after Web 1.0 (2004 onwards). Web 2.0 technologies are far more interactive and mobile than Web 1.0, including social media platforms, wikis, geolocation applications, tagging of content, wireless computing technologies (Wi-Fi) and mobile devices such as smartphones and tablet computers that can provide almost

universal connection to the Internet. Some commentators are beginning to remark upon the emergence of the third generation of the World Wide Web, Web 3.0 (the ‘semantic’ or ‘intelligent web’), involving the Internet of Things, in which sensor-embedded and other ‘smart’ technologies are increasingly interlinked and able to exchange information with each other (Fuchs et al., 2010). While these terms are not necessarily accepted by all Internet commentators and researchers, they do highlight significant changes in Internet, web-based and other digital technologies over the past 20 years.

By the turn of the 21st century, many social scientists were recognising the growing impact of health- and medical-related websites and researched them accordingly. A series of articles reporting such studies were published in *Health* from 2000. Most of these articles on online discussions and information have tended to adopt a similar approach as that taken in traditional analyses of health and medicine in the mass media. The content of websites and online messages or discussions contributed by users have been a central focal point for research.

Diane Goldstein (2000) claims the distinction of publishing the first *Health* article on online forums. She addressed online menopause health support groups and the ways in which participants shared information with each other and challenged both medical authority and feminist pronouncements on menopause. Following Goldstein’s piece, several more articles appeared in *Health*. Most of these studies focused on the meanings concerning health, illness and medicine represented on online forums, information-seeking behaviour and how the public was making sense of the rapidly expanding volume of information on illness, disease and medical treatment that was presented on websites (Ayers and Kronenfeld, 2007; Broom and Tovey, 2008; Fox and Ward, 2006; Guise et al., 2007; Pitts, 2004; Seale, 2006). One author sought to move beyond the focus on lay people and patients to research how medical specialists were responding to patients’ online information-seeking (Broom, 2005), while another article outlined findings from a project seeking to use a health promotion website to effect behaviour change (Lindsay et al., 2008).

Some of these authors have adopted a critical and theoretically sophisticated approach that went beyond description to deeper analysis of the social, cultural and political dimensions. Fox and Ward (2006), for example, drew on Deleuzian theory to ask ‘What can a body do?’ when embodiment and identities are portrayed and negotiated on Internet forums. They examined online discussion groups concerning the use of Viagra, weight loss drugs and pro-anorexia, emphasising the multiplicity of identities and forms of embodiment that receive expression on such sites, from the active consumer of pharmaceuticals to the resistant anti-medicine views that are articulated on pro-anorexia sites. Concepts and experiences of ‘health’ online, they contend, are enactments of bodies, technologies and affects.

More recently published *Health* articles on digital technology topics have tended to continue to follow the same lines of enquiry as earlier authors in focusing mostly on the content of online interactions (Armstrong et al., 2012; Bar-Lev, 2010; Bennett and Gough, 2013; Chapple and Ziebland, 2011; Cimini, 2010; Giles, 2014; Hipple Walters et al., 2015; Hor et al., 2013; Keshet, 2012; McDermott, 2014; Meleo-Erwin, 2011; Veen et al., 2010). Several of these articles have identified nuances in the ways online communities operate and how discussions on these forums reproduce dominant discourses,

moral precepts, norms and assumptions or seek to challenge them. Cimini (2010), for example, examined the attempts to reshape the meanings of disability by activists in online forums, while Giles (2014) addressed the reactions of Asperger's disorder online community to changes in the *Diagnostic and Statistics Manual of Mental Disorders* (DSM) concerning collapsing that disorder into the general autism spectrum. These articles emphasise the important role played by online discussion forums in providing a space for marginalised and disempowered social groups to find each other and provide support.

However, as digital health technologies have become more diverse and complex and opportunities for users to contribute content have expanded, a wider perspective that is able to incorporate analysis of how technologies operate in conjunction with users is important. While social scientific research on telemedicine, one of the earliest forms of clinical digital technologies, has been well researched and published in other forums, only two *Health* articles have discussed it. Cartwright's (2000) article examined the ways in which the discourses and practices of telemedicine generate new definitions of people living in remote areas. She contended that telemedicine offers novel ways of assessing populations and their healthcare requirements and ranking and ordering bodies in the form of 'health communities'. Patients are rendered mobile via these technologies. Their images and other data are able to move across great distances, even if their fleshy bodies cannot. In her analysis of the lived experience of computerised self-dialysis technologies, Shaw (2015) adopted a theoretical approach drawn from science and technology studies in conjunction with Heidegger's phenomenological notion of 'being-in-the-world' that views the human-technology encounter as a form of cyborg embodiment. She used the term 'body-in-dialysis' to highlight the entanglements of digital machine and flesh that are configured when patients use their self-dialysis technologies at home. Shaw identified the ways in which these patients respond emotionally to the technologies they use as part of self-care regimes, their ambivalences about needing these machines to live and how the machines discipline human bodies and everyday practices.

These articles complement Waldby's (1997, 1998) two pieces on the Visible Human Project and the computerisation of medicine. The Visible Human Project, developed by the US National Library of Medicine, provides a detailed three-dimensional (3D) digitised data set of transverse cross-sections of two human bodies, taken from a male and female cadaver. These images are freely available on the Project's website. Waldby discussed the ways in which digital technologies have been used to visually document the human body in ever-finer detail and render these details open beyond the clinic to the viewing lay public. As she noted, via computer imagining technologies the body is increasingly rendered into a digital archive, changing the ways in which we think about and experience bodies. Her work represents attempts to theorise digital medical devices as they enter into the public arena of the Internet, offering new possibilities for lay people to gaze inside the spectacle of the human body.

## Directions for future research

Even while some digital scholars are beginning to make reference to the emergence of Web 3.0 and the Internet of Things, and as the medical and public health literature expounds the

apparent disruptive and revolutionary opportunities offered by digital health, many social scientists are only beginning to recognise the major implications of Web 2.0 for health and medicine. Contributors to *Health* are not alone in this; researchers in the social sciences in general have not devoted significant attention thus far to analysing digital health from a sociocultural and critical perspective. Yet, these technologies are having significant effects not only on the generation and exchange of health and medical knowledge, a major outcome of Web 1.0, but also on ideas and practices concerning how human bodies should be understood, experienced and treated.

Doctors now 'prescribe' smartphone apps to their patients as part of preventive medicine and self-care regimens, while some lay people use self-monitoring apps and devices voluntarily to track their health and fitness. Lay people and healthcare professionals alike exchange experiences and share images on social media sites such as Facebook, Twitter, Instagram and YouTube and specialised platforms such as PatientsLikeMe and Patient Opinion and (for healthcare professionals) Sermo and QuantiaMD. In the United States, platforms like ZocDoc (with associated apps for mobile devices) help patients find doctors and dentists in their local area and make appointments online, as well as read reviews of doctors by other users. Big data analytics are reshaping medical and public health knowledge as part of 'infoveillance' techniques and disease mapping using platforms such as HealthMap and Google Flu Trends. Health promoters are seeking opportunities to use mobile devices to convey their messages; medical students are learning in virtual environments and on virtual patients. Using digital data files, customised 3D-printed prostheses are fabricated to replace human body parts.

Since Waldby was writing about the Visible Human Project, the human body has become even more visible, and its intimate details are more accessible. A proliferation of computerised images of human life from conception to death are now readily available online – on websites such as the Human Embryo Project and YouTube videos of surgery, childbirth and patient experiences of illness. Foetal ultrasound images are routinely posted on Facebook, Twitter, Instagram and YouTube by excited expectant parents. Smartphone apps provide anatomical images for medical students, healthcare professionals and lay people alike. Apps allow pregnant women to document their growing bellies and monitor foetal movements and heart rate, while Twitter hashtags are used to organise conversations around healthcare, medical treatment and patient experiences. Digital self-tracking devices document the bodily activities and functions of their users, while 'selfie' portraits enable people to photograph themselves in various forms of embodiment. The most personal aspects of human bodies are now open to digitisation. Menstrual cycle and fertility monitoring apps for women are among the most popular in the app stores. Insertable vaginal digital devices can be used to monitor women's pelvic floor exercises, sending data to their smartphone app demonstrating their progress. Another set of apps encourages people to monitor their sexual activity based on factors such as frequency, body movements and sounds emitted during sex. Digital gaming technologies such as Wii Fit and Xbox Kinect use sensors to document players' body mass index, activity levels and balance.

As the Internet of Things develops, smart objects that collect and emit digital data on bodies will communicate these data to each other in ever-increasing and intertwined data sets on individuals. Sensors embedded in a range of materials will contribute to this

ceaseless generation of data. In addition to wearable or insertable devices such as fitness trackers, blood glucose monitors and digital tablets that send data wirelessly from inside the body to a patch worn on the arm, the smart chair, smart floor, smart bed, smart home thermostat and smart car that measures bodily movements and functions already exist. Sensor-embedded physical environments that monitor people's movements in public spaces are already in place. Many smart fabrics have been developed that can be used for clothing or footwear to collect body metrics on wearers. The 'healthy' city has been reimagined as the 'smart healthy city' by bringing together personal biometric data collected on individuals with digital data sets on the cities' populations. Citizen science and participatory sensing initiatives involving the collection of environmental data by digital devices as part of crowdsourcing efforts.

A major development in digital health is the emergence of the digital data knowledge economy, in which the personal information that is generated by lay people via their interactions with digital technologies has taken on significant commercial, managerial, research and private value (Kitchin, 2014; Van Dijck, 2013). With the support of ubiquitous mobile computing and the computing cloud, personal data are generated incessantly by users and stored in massive databases. In the context of health and medicine, the term 'patient-generated data' has begun to be employed (Huba and Zhang, 2012). This term refers to the various ways in which patients or their lay caregivers produce information on themselves outside the clinic setting: either voluntarily through self-tracking efforts, remote monitoring self-care devices and uploading material to social media platforms, or as part of routine transactions online. Not all of these data may be in digital form originally – some may involve completing pen-and-paper questionnaires or writing in paper diaries, for example – but most of this material is eventually rendered into digital formats for storage and analysis. These data are then employed for purposes such as health profiling for targeting treatment and illness prevention strategies.

I noted in my introductory remarks above that digital health involves the bringing together not only of new media but also medical technologies and consumer cultures. All three of these realms have become digitised and subsequently are able to interact and exchange data with each other. Given that digital technologies allow for the transfer of data from one object/user to another in binary form via software and wireless and cloud computing, the kinds of information that are generated by one 'smart' device can now be exchanged with or into another object/user. Thus, for example, a wearable device used by a patient for self-monitoring a chronic illness such as diabetes or high blood pressure or a device voluntarily used by a person intent on self-tracking their energy intake and expenditure, physical activity or sleep produces digital data on bodily functions and activities that can be readily uploaded to the software of healthcare professionals (such as patient electronic records) or to social media for sharing with friends. These data may then circulate in the digital data economy, targeted for harvesting by data miners or researchers who are interested in the insights that they may produce for commercial or research endeavours.

Some American hospitals are already working on integrating the data from patients' self-tracking devices with their electronic medical records. This step has been facilitated by the availability of these personal data devices, changing payment for healthcare models in the United States and the development of middleware such as Apple's HealthKit

which assists hospitals in merging these different sources of patient data. Healthcare, pharmaceutical and biotechnology companies are using social and other digital media for marketing and public relations purposes. This takes place in a variety of ways, from the traditional explicit type of marketing, such as sponsoring banner ads and conferences, to the covert, such as attempting to influence social media discussions on platforms such as Facebook or Twitter.

Even the most basic elements of digital health remain under-researched from a social science perspective: in the pages of *Health* and beyond it. Social scientists need to continue to examine online forums and websites but also to move towards analysing the sociocultural implications of such software and devices as apps, wearable devices and wireless self-care technologies. Despite the fact that hugely popular social media sites such as Facebook and Twitter have been in existence for around a decade now, hosting countless discussions of health, illness and medicine; that YouTube offers thousands of videos on health- and medical-related topics; and that Wikipedia is the most highly used reference source globally, these platforms have barely rated a mention in *Health*. People's use of self-tracking wearable devices has not been examined (although a recent *Health* article by Fox (2015) is an attempt to theorise these devices using sociomaterialist perspectives). Nor have aspects of computer code and software or digital data (including big data) received attention. Given the huge number and variety of health- and medical-related mobile apps that are now on the market (over 100,000 of them) (Jahns, 2014), it is surprising that very few social scientists in *Health* or elsewhere have begun to analyse their content and use.

The nature of contemporary digital data practices, or how people make sense of the personal data that are generated from their various interactions with digital technologies, requires critical investigation. There is scant research on how people may seek to materialise these data; that is, manipulate them using various software tools or apps to generate graphs and other visualisations, or even render them into objects using 3D printers. As a growing body of literature on voluntary self-tracking for health and fitness purposes has begun to demonstrate, people respond to the personal data that they generate from these practices in varied ways. For some users, the opportunity to collect highly detailed information about such aspects of their bodies as heart rate, steps taken, diet, body weight and sleep patterns leads to sustained behaviour change and a sense of feeling in control of their bodies and their lives. For others, however, this information may not be useful or applicable to their lives, or they may become bored with using the device (Lupton, 2016). Further research is required that is able to elucidate and theorise how these personal data are incorporated into their lives, and how healthcare and public health professionals are using these data as part of their work. Nor have many studies by social scientists been conducted on how people are responding to the various revelations and scandals concerning the access of people's personal information by government security agencies and hackers, and what are their attitudes concerning health- and medical-related data security and privacy.

The ways in which digital health data are beginning to have material impacts on people's lives is another area of potential research by critical scholars. Workplaces and schools are beginning to require people to use digital monitoring technologies to track not only geolocation, performance and behaviour but also health and fitness indicators

(Lupton, 2015a; Zamosky, 2014). Some researchers have identified the ways in which predictive analytics using the data sets that are generated by people's use of digital technologies are increasingly used to delimit their life opportunities. Based on profiles and inferences that are generated by the data that are harvested on people, decisions are made about employment opportunities, provision of credit and life and health insurance in ways that may further reinforce social marginalisation and disadvantage (Crawford and Schultz, 2014; Rosenblat et al., 2014). It is likely that these uses of personal data will have an increasing impact on life trajectories, requiring continuing close attention on the part of social scientists.

### **Moving forward: relevant theoretical approaches**

New digital technologies and the digital data that they produce require sophisticated theoretical approaches. Given that these technologies involve interactions between humans and non-humans, sociomaterialism offers a particularly useful approach. This perspective has been most commonly articulated in science and technology studies and, in particular, actor–network theory. From this approach, technologies participate as material actors in relationships with human actors to configure human–technology assemblages (Casper and Morrison, 2010; Latour, 2005). Sociomaterialism acknowledges the combination of the material and non-material, the human and the non-human, the fleshly and the ideational in ever-changing configurations. It therefore recognises the dynamic nature of people's interactions with technologies in a world in which the digital is increasingly part of everyday lives, social relationships and concepts of subjectivity and embodiment. It has been employed productively in past analyses of telemedicine (e.g. Mol and Law, 2004; Oudshoorn, 2011; Pols, 2012).

Philosophical approaches that are able to theorise the lived experience of using digital technologies are also important. Several theorists have begun to argue for the concept of the post-human body, in which digital technologies have become so taken-for-granted and elided with human embodiment that humans and technologies are co-evolving (Hayles, 2008). The concepts of the cyborg and cyberspace have become less salient as these blurring of boundaries has intensified (Lupton, 2015b), inciting revised ways to understand the ontology of the entanglements of flesh with technologies. The spatial dimensions of digital health technologies also require attention, particularly as objects and spaces become increasingly embedded with sensors that are able to generate personal health data. The notion of code/space, as outlined in the work of Kitchin and Dodge (2011), develops the idea of geographical space, human bodies and software as working together to generate new knowledge. When human bodies move through sensor-embedded spaces, use smart furniture or smart thermostats in their homes or wear smart clothing or wearable devices – or even simply when they carry their smartphones (which automatically generate geolocational data as they move around) with them they are constantly emitting various forms of digital data.

The post-cyborg body that is now the lived experience of many people is a body in which fleshly and technological entanglements are so familiar, domesticated and unobtrusive that we now no longer think of ourselves as cyborgs even while we are increasingly becoming absorbed into code/space. New formulations of digitised bodies need to

allow for the dynamic nature of digital knowledge and practices of embodiment that involve ever-shifting hybrid forms acting cybernetically as data generated in real time lead to responsive changes, which produce more and different data and so on (Lupton, 2015c). Rather than simply focusing on how people represent or talk about their bodies, more research is required that is able to investigate what they do with devices such as smartphones, wearable fitness trackers or patient self-care technologies; how they hold or wear them as part of enactments of health or medicine; and how they embrace, resist or relinquish their use.

Just as legacy mass media outputs should be regarded as sociocultural artefacts that reflect and reproduce tacit norms and assumptions, so too apps and other computer software such as search engines, browsers, websites and platforms and the devices used by people to access this software require this type of analysis (Lupton, 2014a). Digital health technologies configure a certain type of practising medicine and public health, a certain type of patient or lay person and a specific perspective on the human body. The techno-utopian approach to using digital health technologies tends to assume that these tacit norms and assumptions are shared and accepted by all the actors involved and that they are acting on a universal human body. A cursory examination of surveys of digital health technology use demonstrates that social structural factors such as age, gender, education level, occupation and race/ethnicity, as well as people's state of health and their geographical location, play a major role in influencing how such technologies are taken up among lay people or the extent to which they are able to access the technologies (see e.g. Fox and Duggan, 2013; Kontos et al., 2014). Just as beliefs about health and illness vary from culture to culture, so too do responses to the cultural artefacts that are digital health technologies. Aboriginal people living in a remote region of Australia, for example, have very different notions of embodiment, health and disease from those the ideas that tend to feature in the health literacy apps that have been developed for mainstream White Australian culture (Christie and Verran, 2014). As yet, few other analyses have sought to highlight the social and cultural differences in which people respond to and use digital health technologies.

The subfields of Internet studies, platform and software studies also provide firm bases from which to begin to develop critical digital health studies (see e.g. Fuchs, 2014; Manovich, 2013; Rogers, 2013; Van Dijck, 2013). These approaches develop a critique of digital media and technologies that acknowledges their materiality and political dimensions, with a focus on the ways in which technologies such as code, software and platforms structure the habits and preferences of human users and how the Internet empires such as Facebook, Google, Apple, Amazon and Microsoft have established and maintain their wealth and power. The affordances of technologies such as search engines, or the ways in which they structure user experience and shape the results that are generated, also require analytical consideration. Search engines like Google Search (easily the most highly used search engine), for example, use algorithms that customise searches for each individual user, based on considerations such as what other searches that person has conducted and their geolocation. Search returns are also shaped by factors such as whether website developers have paid Google to promote their site and the volume of searches for the same topic by other Google users. Search engines and their algorithms, therefore, are active participants in meaning-making, defining how people are able to

access information according to their inbuilt assumptions, orderings and values (Roberge and Melançon, 2015; Rogers, 2013).

So too, recent theoretical positions on big data and the algorithms that manage and interpret these data are valuable in understanding the impact of digital data in health and medicine. Critical scholars have recently begun to engage with big data, pointing out the ways in which digital data sets are configured and the political purposes to which they are put. Often drawing on a sociomaterial perspective, these scholars have contended that big data are not the neutral, objective facts they are often represented as in popular discourses. Rather they are positioned as sociocultural enactments, the products of specific interactions between humans and non-humans (Boellstorff, 2013; Kitchin, 2014; Kitchin and Lauriault, 2014). The algorithms that collect and manage digital data contribute to certain ways of categorising and producing subjects and bodies, rendering them into algorithmic assemblages (Striphas, 2015; Totaro and Ninno, 2014). The notion of digital data as lively, constantly circulating and being repurposed in the digital data economy, is important as a way of understanding their ramifications and implications. As I have argued elsewhere (Lupton, 2016), digital data are lively in four major ways. They are about life itself; they have their own social lives as they enter and move around in the digital data economy; they have effects on people's lives; and they contribute to people's livelihoods as part of wealth generation and research initiatives. These perspectives are important in contributing to a full sociocultural analysis of the ways in which people and healthcare institutions construct and convey their knowledge related to health and medicine.

## Concluding comments

Social scientists interested in digital health technologies now have a vast range on which to focus. As I have contended in this article, there are several important topics to direct research and theorising towards in configuring a body of literature in critical digital health studies. These may be grouped around four main themes, as follows:

1. *Devices and software.* What are the digital devices and software that exist; what are their affordances and limitations; what are the mentalities and practices of the developers, entrepreneurs and coders who make and sell them; what kinds of data do they generate; how are their use incorporated into embodiment, identities, everyday lives or the work practices of healthcare and public health professionals?
2. *Data materialisations.* How are digital data represented, visualised or rendered into objects?
3. *Data practices.* How do people generate, upload, seek out and use digital data; how do they make sense of these data; how do these data contribute to concepts of self and embodiment, to quotidian and work lives, to life chances and opportunities and to relations of power (e.g. between patients and healthcare workers or between the owners of digital data and those who want to use these data)?
4. *Data mobilities.* How do lively digital data circulate, how are they purposed and repurposed by different actors and agencies, what are their politics and what are the issues around data security and privacy?

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