



# Beyond Techno-Utopia: Critical Approaches to Digital Health Technologies

Edited by  
Deborah Lupton

Printed Edition of the Special Issue Published in *Societies*



[www.mdpi.com/journal/societies](http://www.mdpi.com/journal/societies)

Deborah Lupton (Ed.)

# **Beyond Techno-Utopia: Critical Approaches to Digital Health Technologies**



This book is a reprint of the Special Issue that appeared in the online, open access journal, *Societies* (ISSN 2075-4698) in 2014 (available at: [http://www.mdpi.com/journal/societies/special\\_issues/health-technologies](http://www.mdpi.com/journal/societies/special_issues/health-technologies)).

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*Editorial Office*

MDPI AG  
Klybeckstrasse 64  
Basel, Switzerland

*Publisher*

Shu-Kun Lin

*Production Editor*

Xingxing Zhao

**1. Edition 2015**

MDPI • Basel • Beijing • Wuhan • Barcelona

ISBN 978-3-03842-060-6 (Hbk)

ISBN 978-3-03842-061-3 (PDF)

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# Table of Contents

List of Contributors ..... V

Preface ..... IX

## **Minna Ruckenstein**

Visualized and Interacted Life: Personal Analytics and Engagements with Data Doubles

Reprinted from: *Societies* **2014**, 4(1), 68684

<http://www.mdpi.com/2075-4698/4/1/68> ..... 1

## **Michael Christie and Helen Verran**

The Touch Pad Body: A Generative Transcultural Digital Device Interrupting

Received Ideas and Practices in Aboriginal Health

Reprinted from: *Societies* **2014**, 4(2), 2566264

<http://www.mdpi.com/2075-4698/4/2/256> ..... 18

## **Emma Rich and Andy Miah**

Understanding Digital Health as Public Pedagogy: A Critical Framework

Reprinted from: *Societies* **2014**, 4(2), 2966315

<http://www.mdpi.com/2075-4698/4/2/296> ..... 27

## **Collette Sosnowy**

Practicing Patienthood Online: Social Media, Chronic Illness, and Lay Expertise

Reprinted from: *Societies* **2014**, 4(2), 3166329

<http://www.mdpi.com/2075-4698/4/2/316> ..... 47

## **Sophia Alice Johnson**

“Maternal Devices”, Social Media and the Self-Management of Pregnancy,

Mothering and Child Health

Reprinted from: *Societies* **2014**, 4(2), 3306350

<http://www.mdpi.com/2075-4698/4/2/330> ..... 61

## **Baki Cakici and Pedro Sanches**

Detecting the Visible: The Discursive Construction of Health Threats in a

Syndromic Surveillance System Design

Reprinted from: *Societies* **2014**, 4(3), 3996413

<http://www.mdpi.com/2075-4698/4/3/399> ..... 83

**Jane Hendy, Theopisti Chrysanthaki, James Barlow**

Managers' Identification with and Adoption of Telehealthcare

Reprinted from: *Societies* **2014**, 4(3), 4286445

<http://www.mdpi.com/2075-4698/4/3/428> ..... 98

**Chris Till**

Exercise as Labour: Quantified Self and the Transformation of Exercise into Labour

Reprinted from: *Societies* **2014**, 4(3), 4466462

<http://www.mdpi.com/2075-4698/4/3/446> ..... 116

**Deborah Lupton**

Apps as Artefacts: Towards a Critical Perspective on Mobile Health and Medical Apps

Reprinted from: *Societies* **2014**, 4(4), 6066622

<http://www.mdpi.com/2075-4698/4/4/606> ..... 134

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**Jane Hendy** is senior lecturer in the Department of Healthcare Management and Policy at the University of Surrey. Jane previously held positions at the Imperial College Business School, University College London, and the London School of Hygiene and Tropical Medicine. Jane's research focuses on the organisational change and integration attached to the adoption of innovations in health care, particularly telehealthcare. Jane has studied the national rollout of telehealth care services over the last five years—more recently as part of the evaluation team for the Department of Health's Whole System Demonstrator Programme.

**Sophie Johnson** is an early career researcher with an interdisciplinary background which intersects gender, health, sociology and technology. Her interests lie in the implications of technology and big data for health care and quality of life. Her PhD research, which was completed at the University of Sydney, investigated the health information-seeking experiences of women transitioning to first-time motherhood. This included a focus on the user experiences of women accessing the internet as a form of social support and knowledge-gathering, and utilising applications (apps) in a variety of ways including tools of convenience, knowledge-gathering, tracking functionalities and push notifications. She is very interested in working to adopt and test new methodologies of research for investigating the use of digital technologies for health and well-being. She is not only interested in why people use digital health technologies, but also the ways these technologies can impact on identity making and identity management.

**Deborah Lupton** is Centenary Research Professor in the News and Media Research Centre, Faculty of Arts and Design, University of Canberra. She has published widely on the sociocultural dimensions of medicine and public health, risk, the emotions, food, obesity politics and parenting. Her current research is focused on digital technologies in relation to a range of topics, including medicine and health, big data, self-tracking, parenting and academic work. She has published 14 books, the latest of which is *Digital Sociology* (2015, Routledge). Her blog is 'This Sociological Life'.

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**Pedro Sanches** is a researcher in the field of Computer Science. Pedro combines the design and engineering of ICT-based surveillance with a critical stance focused on the implications of surveillance, which draws on theory and methods from science and technology studies. He received his PhD degree in 2015 from the Royal Institute of Technology, Department of Software and Computer Systems. His doctoral research focused on health data analytics, and included cases of self-surveillance, with a focus on personal informatics applications, and of mass-surveillance, with a focus on syndromic surveillance. His dissertation is titled 'Health data: representation and (in) visibility'. Previously, Pedro has worked in the Swedish Institute of Computer Science, and in the Mobile Life Centre.

**Collette Sosnowy** is an Assistant Research Professor with the Research Program in Life Course Outcomes at the A.J. Drexel Autism Institute at Drexel University in Philadelphia. She earned her Ph.D. in psychology from the CUNY Graduate Center, where her research focused on health information and social media, specifically how laypersons develop medical expertise and use social media to share and build knowledge. Her emerging research examines online communities and disability rights activism by people on the autism spectrum. She has a strong interest in making scholarship public, accessible, and engaging, especially through digital forums, and leads media and communications for the Life Course Outcomes program. Collette has also taught at Brooklyn, Hunter, and Sarah Lawrence Colleges, held fellowships in writing pedagogy, digital research, and health education, and worked as a journalist.

**Chris Till** is a Senior Lecturer in Sociology at Leeds Beckett University and has degrees in sociology and social research as well as a PhD in sociology from the University of Leeds. His research focuses on bodies, particularly in relation to health, technologies and gender and is currently conducting research into the corporate use of digital self-tracking. All of his work is informed by contemporary social theory especially that which is engaged with governmentality, Marxism, subjectivity and actor network theory. He has published work in the journals *Thesis Eleven*, *Health Sociology Review* and the book *Bauman's Challenge: Sociological Issues for the 21st Century*.

**Helen Verran** is a comparative philosopher. She now works with Michael Christie in the Contemporary Indigenous Knowledge and Governance research group after leaving the University of Melbourne where she taught History and Philosophy of Science for nearly twenty five years, in 2012. She and Michael first met in 1986 when she worked with Yolngu knowledge authorities at Yirrkala School in the Northern Territory helping devise an innovative mathematics curriculum giving equal importance to both the Yolngu knowledge and traditional mathematics education.





# Preface

The title for this special issue was devised as a direct challenge to the prevailing solutionist and instrumental approaches to the application of digital technologies to medicine and public health. In formulating the idea and title for the special issue, I wanted to inspire some provocative and challenging commentary and research on what I interpreted as a dominantly techno-utopian position on digital health. One important approach that I particularly wanted to encourage, and which I articulate in my own contribution to the special issue, is that which views digital health technologies as social, cultural and material artefacts which have political implications and embodied entanglements with humans and other nonhuman actors.

Three waves of digital technology adoption have been identified in healthcare. The first wave began in the 1950s, when nascent computerised technologies were used to automate standardised and repetitive tasks such as accounting and payroll-related data entry. Health insurance companies and other industry stakeholders also used computers to analyse data. The second wave of digital technology use in healthcare emerged in the 1970s, incorporating the development of health informatics and electronic health card systems. Both waves incorporated individual institutions establishing systems for more efficient data management and processing. The third wave is emerging in the current era. This wave sees moves towards the digitisation of as many elements of healthcare as possible and the interaction and exchange of data between different institutions and systems: an overarching framework that incorporates data not only from healthcare institutions and systems but actors and agencies outside this sector [1].

Over the past few years, an emerging discourse on digital health technologies (also referred to as mHealth, eHealth, connected health and Health 2.0) has represented them as offering unprecedented solutions to the “wicked problems” of medicine and public health. In popular forums, among digital developers and entrepreneurs and in the medical and public health literature a constant refrain has insisted on the “disruptive” and “revolutionary” nature of these technologies and their potential to address budgetary constraints and healthcare delivery limitations and to facilitate health promotion, preventive medicine and public health surveillance. Digital health technologies encompass a wide range of devices and software. These include the use of social media by both members of the lay public and healthcare or public health professionals to discuss health and medical issues and disseminate information; remote healthcare consultations and patient self-care using digital technologies (telemedicine and telehealth); the use of virtual reality in medical training; the rapidly expanding number of mobile applications (“apps”) devoted to health and medical matters (now numbering in the tens of thousands); health informatics systems in healthcare delivery; public health surveillance using big data to track disease patterns; wearable self-tracking devices and gaming technologies for monitoring bodily functions and activities using sensors; health promotion employing social media and text messages; 3D printing of medical devices and prosthetics; and community development and activist initiatives involving citizen science/citizen sensor activities to generate environmental information on their local area (see overviews in [2,3]).

Digital health technologies and the medical gaze extend well beyond the clinic. They now penetrate into many social domains and intersect with a multitude of objectives and purposes. It is clear that health monitoring technologies and the personal data that they generate are viewed as significant commercial opportunities for digital developers. Major companies such as Apple, Samsung, Microsoft and Google are now entering the digital health arena: all four announced their plans to launch health and fitness tracking platforms in 2014. 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. The collection of personal data by self-tracking devices has been taken up and repurposed by employers, educational institutions, health and life insurance and customer loyalty programs [4]. These technologies bring voluntary individual health-related behaviours (such as a lay person choosing to download a health-related app) or communal sharing of experiences (as in patient support platforms such as PatientsLikeMe) together with the imposed or “pushed” use of devices (for instance patients being sent home from hospital with wireless self-monitoring technologies) and the use of people’s personal digital data by actors and agencies for their own managerial or commercial purposes, often without people’s knowledge or consent (for example the “harvesting” of social media content by biopharmaceutical companies) [4].

While there is an extensive literature on older forms of digital technologies that have been used for health and medical purposes (such as blogs, websites and telemedicine), academic researchers, particularly in the social sciences, have yet to devote much attention to the newer technologies that have emerged over the past half-decade or so: apps, wearable and citizen sensing devices and 3D printing, for example. Most of the publications that have appeared on these topics have been published in the medical and public health literature. The writers take a largely instrumental approach that is interested in the efficacy of digital technologies or professional issues such as accuracy of the information provided or conflict of interest concerns. For example a recent meta-analysis of the literature that has been published investigating social media use in medicine and healthcare found evidence of the growing use of social media in these sectors. The authors identified across these publications recurrent themes related to ethics, professionalism, privacy, confidentiality and information quality [5].

The available information on the usage statistics of digital technologies mostly comes from market research, although the Pew Internet Center has also conducted valuable surveys on the American population. A 2013 Pew report noted that 59 per cent of American adults said that they had searched online for health-related information, with over one-third of their respondents reporting using the internet to self-diagnose or diagnose someone else’s condition [6]. Recent market research surveys have found that more than a third of American doctors had recommended that their patients use a health or medical app and that almost one-third of American smartphone owners had used health and fitness apps [7]. However, while a great deal of hype and excitement have been expressed about the possibilities and potential of digital health in entrepreneurial digital developer circles and news reports, the reality of use does not always reach expectations. For example other market research has found that while in 2013 one in ten American adults owned a digital fitness tracker, a high proportion of

people (more than half) had relinquished their use; one third had given up using it within six months of purchase [8].

The articles in this special issue build on a well-established literature in sociology, science and technology studies and media and cultural studies that has addressed the use of digital technologies in health and medicine. This research has particularly focused on patients' and healthcare professionals' experiences of telemedicine and telehealth, lay people's use of websites and social media for seeking information about health and medical topics and sharing experiences of specific conditions, the inequalities that are evident in different social groups' use of digital technologies for health- and medical-related purposes and the sociocultural dimensions of the digitising of human bodies (see [2] for a review of this literature). Studies on patients' experiences of using digital technologies for at-home self-care, for example, have demonstrated the complexities, ambivalences and strong emotions that are involved. Patients may find using these devices empowering, allowing them to reduce travel to see their healthcare provider or to live independently at home. However, many patients resent the incursion into their homes of medical devices that constantly remind them that they are old and infirm or are dealing with a serious chronic illness, or make them feel that they are under constant surveillance. Furthermore, while the devices promise certainty and simplicity, they are often difficult to use and ambiguous in the information they convey [9–13].

Several of these topics are taken up in the articles published in this special issue. All the authors use social and cultural theory to provide insights into the tacit assumptions, cultural meanings and experiences of digital health technologies. The articles cover a range of digital health technologies: devices used for the self-tracking of body metrics (Ruckenstein; Till; Rich and Miah; Lupton); social media platforms for discussing patients' experiences of chronic disease (Sosnowy) and experiences of pregnancy and early motherhood (Johnson); health and medical apps (Till; Johnson; Christie and Verran; Lupton); telehealthcare systems (Hendy, Chrysanthaki and Barlow); and a digital public health surveillance system (Cakici and Sanches). While some articles focus on globalised digital media (Cakici and Sanches; Rich and Miah; Till; Lupton), others engage more specifically with a range of sociocultural groups, contexts and locations. These include Aboriginal people living in a remote region of Australia (Christie and Verran) and Australian mothers in urban Sydney (Johnson) as well as research participants in Helsinki, Finland (Ruckenstein), the United States (Sosnowy) and England (Hendy, Chrysanthaki and Barlow).

Understandings and experiences of selfhood and embodiment as they are generated and experienced via digital health devices are central preoccupations in the articles by Ruckenstein, Rich and Miah, Till, Lupton, Sosnowy and Johnson. Ruckenstein's study of self-trackers found that they often conceptualised their bodies and their physical activities in different ways when these were being monitored and rendered into digital data. The data that were generated by these devices proved to be motivational and to give value to some activities (like housework) that otherwise lacked value or new meaning to functions such as sleep (which when digitised and quantified became viewed as a competence). Ruckenstein found that the digital data tended to be invested with greater validity than were other indicators of bodily wellbeing or activity, such as the individual's physical sensations.

All of the above authors comment on the ways in which digital health devices such as wearable self-tracking devices, social media platforms, apps and patient support websites work as disciplinary tools. They invite users to conform to the ideals of healthism (privileging good health above other

priorities) and the responsible self-management and self-monitoring of one's health and body, including avoiding exposure to risk. Rich and Miah use the concept of "public pedagogy" to describe the socio-political dimensions of digital health technologies as they are employed to educate people about their bodies and promote self-management. As Johnson notes, for women who are pregnant or have the care of young children, this sphere of responsibility is extended to the bodies of others: the foetus or child. And as Till's article emphasises, when employees are "encouraged" to engage in self-tracking, the ethos of responsibility extends from personal objectives to those of employers.

Ruckenstein, Till and Sosnowy also highlight the digital labour involved for people who engage with social media or self-tracking apps as part of their personal health or fitness practices. Sosnowy's interviews with women with multiple sclerosis who blog about their condition emphasise the work involved in such engagement as an "active patient". Till's analysis of digital exercise self-tracking, points to the appropriations of people's labour by other actors for commercial reasons.

The article by Hendy, Chrysanthaki and Barlow moves in a somewhat different direction. Using ethnographic cases studies, they look at the managerial issues involved with implementing telehealthcare in English social and health care organisations. Their focus, therefore, is not on the recipients or targets of digital health technologies but rather those who are attempting to institute programs as part of their work as managers. These authors' contribution highlights the messiness of introducing new systems and practices into large organisations, and the resistances that may emerge on the part of both workers and the targets of telehealthcare programs. Cakici and Sanches' article also takes an organisational perspective in addressing a European Commission co-funded project directed at syndromic surveillance, or the use of secondary sources to detect outbreaks and patterns in diseases and medical conditions. Digital data are increasingly being used as part of syndromic surveillance: Google Flu Trends is one such example. Cakici and Sanches' analysis highlights the role played by human decision-making and the affordances of digital technologies in structuring what kinds of data are retrieved for syndromic surveillance and how they are interpreted.

While there are as yet few detailed ethnographic accounts of how people are implementing, adopting or resisting contemporary digital health technologies, there are even fewer that investigate the use of these technologies by members of cultural groups outside the global North. The article by Christie and Verran takes a much-needed diversion from perspectives on white, privileged groups to Aboriginal people living in a remote part of Australia. As they argue, the concepts on health, illness and the body that are held by this cultural group differ radically from the tacit assumptions that are invested in mainstream health and medical apps. Any app that is developed to assist in health literacy that is targeted at this group must incorporate culturally-appropriate modes of communication: positioning people within their cultural and kinship networks of sociality, for example, rather than representing them as atomised actors.

The articles collected here in this special issue have gone some way in offering a critical response to digital health technologies, but they represent only a beginning. Many more compelling topics remain to be investigated. These include research into the ways in which lay people and healthcare professionals are using (or resisting the use) of social media, apps and self-monitoring devices for medicine and health-related purposes; the implications for medical power and the doctor-patient relationship; how citizen science and citizen sensing are operating in the public health domain; the development of new digital health technologies; the implications of big data and data harvesting in

medicine and healthcare; the spreading out of health-related self-tracking practices into many social domains; the unintended consequences and ethical aspects of digital technology use and their implications for social justice; and data security and privacy issues.

Deborah Lupton

*Guest Editor*

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# Visualized and Interacted Life: Personal Analytics and Engagements with Data Doubles

Minna Ruckenstein

**Abstract:** A field of personal analytics has emerged around self-monitoring practices, which includes the visualization and interpretation of the data produced. This paper explores personal analytics from the perspective of self-optimization, arguing that the ways in which people confront and engage with visualized personal data are as significant as the technology itself. The paper leans on the concept of the “data double”: the conversion of human bodies and minds into data flows that can be figuratively reassembled for the purposes of personal reflection and interaction. Based on an empirical study focusing on heart-rate variability measurement, the discussion underlines that a distanced theorizing of personal analytics is not sufficient if one wants to capture affective encounters between humans and their data doubles. Research outcomes suggest that these explanations can produce permanence and stability while also profoundly changing ways in which people reflect on themselves, on others and on their daily lives.

Reprinted from *Societies*. Cite as: Ruckenstein, M. Visualized and Interacted Life: Personal Analytics and Engagements with Data Doubles. *Societies* **2014**, *4*, 68684.

## 1. Introduction

With smart phones and tracking devices, measuring and tracing aspects of “the personal” and “the everyday” is becoming more commonplace. A field of personal analytics has emerged around self-monitoring practices such as the measuring and tracking of physiological reactions, movement, and activities of individuals; the sharing of the data with others; and the interpretation of data produced [1–3]. This article approaches personal analytics through two interrelated themes that have been identified as formative in this field: visibility and self-optimization [3–7]. Self-monitoring is a practice that seeks to make known something that is typically not a subject of reflection, with the aim of converting previously undetected bodily reactions and behavioural clues into traceable and perceptible information. Consequently, the design and technical specifications of tracking technology builds on the notion that visibility is desirable and that it is of value for people to have their physiologies and everyday movements made observable and legible.

The theme of visibility links personal analytics to modern notions of control and governmentality, the idea being that by making unknown aspects of bodies and lives detectable, we can gain more control over life processes and entities [4,7,8]. From this perspective, personal analytics is part of the history of conquering previously unexplored areas by making physiological responses and behavior—heartbeat, everyday movements, the number of steps taken and so on—available for mapping and tracking. Smartphone applications and other monitoring devices act as mediators and translators that contribute to opening a widening field of everyday life to scrutiny and intervention, connecting with the theme of self-optimization. Personal analytics is thus firmly rooted in the externalization of “nature” as something that people are able to transform: when



bodies and lives are made more transparent, they can be better acknowledged and acted upon. With the aid of digital technology, particularly the tracking and monitoring of the self, optimization becomes not only possible, but also desirable. It is not enough to have a more transparent view of oneself, one needs to respond to that knowledge and raise one's goals, thereby framing the "natural" body as incomplete, as failing the demands and potentials of the information age [7]. With new data streams, the body may be increasingly controlled by reason; it can be transformed and improved in order to attain happiness and excellence. As Viseu and Suchman [7] (p. 163) argue: "the greater visibility of bodily information implies an associated responsibility to act".

The following discussion is shaped by these defining themes but, rather than reifying them, the aim is to explore how they are played out in relation to personal analytics. Both visibility and self-optimization are regarded as active processes and desires rather than static qualities of presence or absence. It is suggested that in order to engage with these processes in a more detailed and reflexive manner, it is crucial to understand how people confront and interact with their own data. I rely on the concept of "data double" [5] (p. 237); [9] (p. 606) previously discussed in the field of surveillance studies. Haggerty and Ericson [9] refer to operations that first abstract human bodies by separating them into various data flows or streams and then reassemble them into data doubles to be analyzed and targeted for intervention. The aim here is to illustrate that by promoting processes that abstract and slice "the self" into various kinds of data flows, self-monitoring enables the making of personal data doubles. Technologies offer partial vistas of people's lives in the form of data doubles that become part of processes of knowledge formation; data doubles are ways of knowing that can be reflected on and used for various purposes.

The article presents, via an empirical self-monitoring study which produced data generated by heart-rate variability measurement, some characteristics and potentials of people's engagements with data doubles in order to emphasize the active, but also partial, nature of visibility and self-optimization. The study offers observations of how people understand and react to personal data and find value in it. By bringing to the fore ways in which people want to make use of their data doubles the discussion underlines the fact that a detached theorizing of personal analytics is not enough if one wants to capture more affective and wishful ways in which people become involved with their data. People undertake personal analytics as data emerge; while being shaped by self-tracking technologies, they also, in turn, shape them by their own ideas and practices. Data doubles operate as triggers for intervention, as shared artifacts for co-constructing and negotiating meaning: mediators that guide behavior and stimulate discussions and negotiations around personal analytics. From this perspective, digital devices and the data that they generate are material to people's lives and a part of knowing and valuing those lives [10].

## **2. Engagements with Data Doubles**

Not much empirical research has been conducted on everyday uses of self-monitoring. However, with its emphasis on visibility and optimization, self-monitoring sits comfortably within well-known Foucauldian themes [5,11]. Monitoring and tracking technologies create a "techno-gaze" that can be directed towards the user: measuring devices offer insights into personal data flows by making them comprehensible and actionable in terms of individual and biopolitical aims. In other

words, tracking devices offer and arrange physical and metaphysical information by encouraging and persuading the measured to engage with it. Useful here is also the concept of governmentality, and associated technologies of the self, that explain processes that aim to auto-regulate and auto-correct selves through various kinds of therapeutic and health-related techniques [11] (p. 46). In the area of personal analytics, processes of governmentality become observable as mundane attempts to auto-correct bodies, minds and everyday doings. Less than representing a desire to be surveyed and disciplined by an outside force, personal analytics are aimed at detecting likely occurrences of diseases, anomalies or deviant behavior. The more strongly emphasized the moral imperative of healthiness, the more people feel they need to pursue it [12]. Thus, the aim is to minimize unhealthy and deviant behavior and maximize healthy behavior.

An important arena for observing these kinds of auto-regulative processes of everyday governmentality is the Quantified Self movement that started in California in 2008 [1,13]. *Wired* magazine, one of the main advocates of the QS movement, has openly promoted self-optimization and “living by numbers” [14]. The theme of optimization has become an important element of the QS movement via maintaining an optimistic and solution oriented quality to the discourse on personal analytics. Typical of the QS activists’ experiments is that they collect data for analysis with their smartphones and via other measurement techniques and devices, then present the data in QS meetings and online. Personal data and insights gained on “the self” are discussed and circulated so that others can learn from them and perform similar experiments. Significant is the fact that the participants of the QS movement are mostly healthy; they are trying to “optimize their healthiness” by making their bodies and minds more legible through measurement data.

The search for visibility and self-optimization suggests that by applying Foucauldian themes to personal analytics we gain a relatively sound description of what self-monitoring does. Most avid self-trackers have not only internalized the desire to know and to optimize, but also voluntarily act on it by sharing information about their tracking experiments and experiences with their friends and followers, who are invited to monitor their bodily habits and mental states in similar ways. More detailed inquiries into personal analytics and the QS movement, however, also indicate other directions worth exploring. While people distribute, share and compare their data, the notion of personal analytics promotes numerous ways of relating to data, others and selves [5,13]. Thus, it is worthwhile to treat personal analytics as an emerging field of interactions that consists of various kinds of practices and purposes. The Quantified Self movement might appear to be straightforward group self-optimization (or self-optimization in groups), but it is in fact an important site for questioning the meaning and value of self-monitoring devices and related data flows [13].

In order to attend to additional routes in exploring personal analytics, the aim here is to open for scrutiny ways in which data flows might participate in processes of knowledge formation. I have suggested that self-tracking tools abstract human bodies and minds into data flows that can be used and reflected upon. Data doubles are decorporealized and decontextualized bodies—hybrid composites of information—in ways that are intended to encourage people to act in certain ways [5] (p. 237). Importantly, however, recontextualized data doubles might also argue against, ignore, or bypass normative notions of auto-correcting and transforming selves. For instance, anorectics participating in pro-ana online communities share weight-loss tips and offer “thinspiration”

to involve and encourage others in body projects [15,16] which can take advantage of various forms of self-tracking, including self-monitoring devices, in order to be achieved.

Active relationships with personal data underline the fact that personal analytics is emergent and unstable in its goals, characterized by diffuse processes of power that spread over many kinds of networks. This paper offers one possible window onto these processes by demonstrating that people are not only gathering and reflecting on the data, but harnessing it to personal and collective value projects. While interaction and negotiation with data doubles open new kinds of personal vistas, research has demonstrated that personal analytics also creates opportunities for animating the world in ways that are not so obvious. Following Thrift [17] (p. 22), data production through self-tracking can also “frame the world in new ways which deliver a kind of structured uncertainty from which it is possible to detect new things”. As they contemplate the value they supply to the curves depicting physiological reactions to various stimuli, people learn “things” of which they may have been previously unaware. Rather than seeing the person engaging with the data as a bounded entity with a stable and fixed ontology, it might be instructive to appreciate him/her as in a constant state of movement towards becoming, directed by a desire to detect and form new alliances or entities.

### **3. Motivations for Measuring Life**

The empirical part of the article is based on a research project conducted at the National Consumer Research Centre in Helsinki (a collaborative effort by Mika Pantzar, Veera Mustonen and Minna Ruckenstein). In spring 2012, we collected, in co-operation with VTT Technical Research Centre of Finland, an extensive body of material composed of both quantitative and qualitative self-tracking data. From the perspective of personal analytics, aggregated data can be used to identify bodily reactions and behavioural regularities, while the qualitative data might, for instance, describe the ways people experience and give meaning to measured elements in daily life [18]. With their own questions and insights, research participants can deepen the correlations found in numerical data and provide bases for an understanding of what measurement data represents and does to people. Out of the large body of data, this discussion particularly focuses on the gathering of the qualitative elements. The aim is to describe what the data gathering process can teach us about personal analytics as an object of study and a field of interactions.

Data collection was supported by Finnish technology companies Vivago and Firstbeat who provided equipment that included a wrist watch measuring activity levels (Vivago), and a heart-rate variability monitor in the form of two electrodes taped on to the skin of the chest (Firstbeat). Evidently, by using marketed tracking devices in our research design, we too became part of the self-tracking market. From this perspective, our research takes place within a collaborative economy wherein market agents promote research that takes advantage of their devices in order to gain legitimacy and reinforce the credibility and reliability of their offerings. We decided to co-operate because we could not have realized our research otherwise. Not naming the companies was an option we considered, but we felt that it was important in terms of our research results to make known our collaborators. The association with technology companies means that this study has an inbuilt tension that cannot be resolved; we could only deal with it by being reflexive and

open-minded about the goals of our research. This research stance was an intentional counterbalance to the device market that tends to represent personal analytics in a programmatic and decontextualized manner: as a solution rather than a starting point. Conversely, we were curious to observe what is actually being promoted by confronting people with digital devices and the data they generate.

Much of the output of self-monitoring devices and mobile health applications, including the data that they generate, fails to engage people [19]. Therefore, one cannot take for granted that the data flows produced by health and wellness devices and applications are of interest to their users. For our research participants the data generated by the Firstbeat device turned out to be most rewarding, despite the fact that they had no access to their recorded data during the measurement period. Some research participants did, however, comment on the fact that we used “old-fashioned equipment”, because many of the self-tracking technologies currently available generate real-time data and monitor the individual in the everyday as it unfolds. Thus the Firstbeat data, based on physiological research on autonomic nervous system function, is analyzed with a temporal delay. Since we are not medical experts and had no access to the algorithms producing information and visualizations on exercise and physical activity, and stress and recovery, we had to take for granted the physiological model underlying the data analysis [20]. We made clear to our research subjects that we were not in the position to critically evaluate the “truthfulness” or “accuracy” of the heart-rate variability data and, therefore, our aim was to understand what happens after the data is brought into people’s lives.

The data gathering was carried out in two parts in order that the findings from the first round could be used for correcting and supplementing the research design of the second round. Both rounds had twenty participants; altogether, we had 36 research subjects, four of which participated in both rounds. All lived in the Helsinki Metropolitan Area, and most were in regular employment. Participants were required to be in good health, meaning that they had no chronic illnesses and used no regular medication. The very first research findings cast light on the relative desirability of becoming a contributor in a self-tracking experiment. We learned that people with a systematic and disciplined relationship to sports and exercise, or an interest in monitoring technologies, are particularly drawn to this type of research; one third of our research participants were active in their chosen sports at least four times a week. Indeed, we had to deliberately restrict the number of active athletes in order to get a more heterogeneous participation. In contrast, those in poorer physical condition, who suspected that they might be overly stressed or misusing alcohol, were likely to decline the invitation to participate. Thus, people were keener to participate if they longed for information, guidance, encouragement, training, and intervention, and wished to become measured, evaluated, and challenged with data flows.

Before the study period began, an initial survey was carried out with the participants. After this, they were interviewed both by e-mail and face to face. In addition to being instructive of people’s interests and aims, the interviews were a way to commit the participants to the demanding data collection process; they had to agree to carrying the research equipment with them, worn directly on their skin, for a little over a week, day and night. The interviews proposed a plethora of motivations for taking part in the study, highlighting the various issues that the research

participants thought they could learn from and solve by self-measuring. In the Northern European context, motivation to use tracking devices is connected to discourses of public health risks which focus on physical conditions brought about by unhealthy diet, lack of physical exercise and alcohol consumption, and resonate at times with a notion that people who do not take care of themselves appropriately are responsible for life-style related diseases [11] (p. 43). Some interviewees stressed the importance of well-being in relation to society; others described in detail how they wanted to become better athletes, spouses, parents and workers. One of the mothers, barely in her thirties, wanted to provide an encouraging example to her children and to improve her stamina at home and at work. She also mentioned a sense of responsibility for her own health, related to ageing, and in relation to the welfare state.

And now that the years are piling on, I find it more important to be able to look after myself when I'm old and not be at the mercy of others. [21]

Overall, the interviews underlined the fact that our research design resonated with questions and expectations that people already had and that they thought that they could explore through personal analytics. Many of the participants wanted to learn more about stress and recovery while others had a hereditary susceptibility to hypertension or cholesterol levels that they wanted to manage better. One of the men, in his forties, said that his father had died of a stroke relatively early, so he needed to take the “cholesterol threat” seriously. Younger participants had suffered from burnout or over-training and they wanted to understand how to balance their daily lives more effectively. It became obvious that many of the research participants wanted the self-tracking period to become a catalyst for change. For instance, a 40-year-old female professional described her expectations in the following manner:

Of course, it will be interesting to see an outsider's opinion of my daily routines, especially because I know that I sometimes go against principles that I know to be good. For example, I sometimes notice that I'm getting stressed, but the deadline is looming. Sometimes my ambition and/or sense of duty takes precedence over my well-being. I expect that the study will make me observe my everyday stress-inducing behavior in a new way—and maybe help me reduce it. [22]

Earlier research has demonstrated how visualized data appears to have agentive force [23]: it pushes people to act and reflect. One of the women, who had recently divorced after a long marriage and was looking for a new direction in life, believed the self-tracking study might help her find it. She said she dreamt of having a personal trainer who would create a training program for her and make her follow it:

I would like to get so fit that someone who hasn't seen me for six months would say “Wow!” to me and ask me what had happened. Because I think I would be able to do it, but the reason it doesn't get done is that I do nothing to get it done. [24]

These kinds of insights expose a desire to find an external motivator: self-monitoring appears to be a method of persuasion. By using the monitoring devices, research participants not only agreed to their bodies being deconstructed into data flows, but they expected the data flows to act on them.

In another example, a mother of small children, in her late twenties, who said she suffered from a lack of exercise and a constant craving for sweets, wanted our research to help her take control of her life. These desires are not surprising, given that self-monitoring underscores what is physiologically valuable and worth pursuing. During our research process, we also actively tried to deconstruct normative notions of self-monitoring by underlining the fact that certain expectations of normality, health and self-optimization are intrinsic to tracking technologies. The idea was to offer room for reflexivity for research participants during the data gathering (see below). Still, this normative bias remains inbuilt in a research design that takes advantage of tracking technologies that analyze data in order to detect normalities and abnormalities. In retrospect, the normativity of our research design was a more pressing ethical concern for researchers than for our participants, whose involvement had indicated that they accepted the fact that the emphasis on greater control of individual bodies and minds was inscribed into this type of research experiment.

#### 4. Being Monitored

Earlier studies combining qualitative and quantitative data demonstrate that data produced by research participants have a more consistent quality if the subjects feel that they have mastered the use of the study equipment [18]. In other words, the better the subjects control the equipment, the less cumbersome and conspicuous it is for them. Without pronounced distance from the digital devices or friction with them, the technology becomes less annoying, moves into the background and might even be experienced as an extension of the self [25]<sup>1</sup>. We wanted to ensure that none of the participants abandoned data collection because of the equipment, and the process was explained in detail during the joint initial meeting where the participants were given the equipment and a promise of technical support. In addition, I kept in contact with them during the data collection process by e-mail in order to discuss the experience of being measured. One of the participants, for instance, described how the electrodes of the heart-rate variability device initially made her feel as if she had just escaped from hospital. Soon, however, she got more accustomed to the measuring apparatus and it no longer bothered her.

In terms of research methodology, online conversations are a way to involve people, because they provide an easy and immediate way to share observations. The ongoing dialogue opens a space for a more participatory research approach; when subjects talk about their experiences while being monitored, they spotlight tensions and findings related to self-monitoring.

Researcher (M.R.), 22/3/2012:

Have you noticed that you pay more attention than usual to what you do and how you or your body feel(s)? Many other participants have mentioned this. If you have noticed this, can you give any examples?

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<sup>1</sup> See, for instance, an ethnographic study of commercially developed insulin pumps that demonstrates how the pump allows young people to be more in charge of their diabetes; they can even forget that they have it. The pump becomes “second nature” [25] (p. 145).

Participant (female, 34 years), 25/3/2012:

I haven't managed to forget about the equipment, I'm still more alert to how my body feels than usual. But I've really tried to take each day as it comes and not start "performing".

Last night, I noticed that the measuring equipment suddenly started physically annoying me quite a lot. I would have liked to rip it off, even if just for the night. But I stayed strong.

Not surprisingly, the monitoring equipment made people more alert to their bodily reactions and everyday doings. When explaining their heightened awareness, they noted, for instance, the attention they were paying to their eating, alcohol consumption, exercise and bodily sensations. In their messages, they also played with the idea of being subjects of control and surveillance, referring to themselves as laboratory rats or residents of the Big Brother house. Due to the nature of our research, the research participants did not treat the surveillance that they were exposed to as a threat to their identity or privacy, but it was an aspect that they recognized and wanted to comment on. A similar recurrent topic was the persuasive and motivating quality of technology, linking to the theme of self-optimization, which we discussed in the emails:

Researcher (M.R.), 24/3/2012:

We have now reached the halfway point in the monitoring period. How are you doing? Have you noticed that you've changed your behavior? I've noticed from other responses that people have stopped snacking so that they don't have to write the snacks down. And they may be keener to go jogging too. Is it the technology that motivates, or is it the fact that you are part of a research project?

Participant (male, 35 years), 24/3/2012:

It's going well. I don't usually snack anyway, but I have noticed that I have not wanted to miss any exercise. This is the thing I find interesting and would like as much information about as possible. In other words, the technology does motivate me :) I'm intending to take a proper fitness test at some point to find out my threshold heart rates and maximum oxygen uptake. Not that there would be any use for this information, but it would be nice to know.

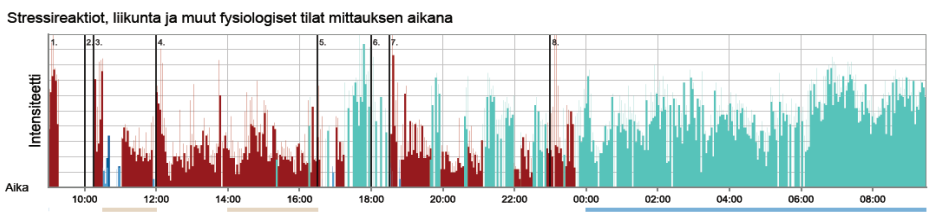
For many participants the tracking technology became a daily companion during the research process, a silent persuader that made sure that the daily workout was not missed, and that one walked to work instead of driving or taking public transport. After the monitoring period ended, some people missed the equipment, regretting that they were no longer persuaded and motivated to behave in ways they felt were right. This acceptance of self-tracking technology as a participant and co-producer of knowledge in people's lives highlights the desire to involve it in daily efforts to improve their existence. Thus self-monitoring devices are often seen as benevolent and responsive, not least because it aids people in coping with prevailing moral imperatives of being healthy and becoming healthier [5] (p. 240). Many of our research participants expressed an interest in continuing with self-monitoring in the future and aimed to download mobile applications for support. They said, for instance, that they were fascinated by the ways in which combining different data flows might deepen their bodily understanding and self-awareness. One of the participants, in his

late twenties, was impressed by the way in which the data could offer him practical and everyday means to influence his life and advance his happiness. The value of real-time data in promoting immediate response to personal choices was also mentioned.

## 5. Visualizing and Interpreting Life

After the monitoring period, the subjects received an illustrated report based on Firstbeat HEALTH-software analysis (see Figure 1) of their heart-rate variation that included their own entries about their everyday doings. With its colors, curves, and bars, the report represents stress and recovery measurements: red indicates stress reactions, green is recovery, blue exercise, and white something in between. The numbers in the chart refer to self-reported activities in the course of the day, the mauve lines under the chart refer to working hours, and the blue line to sleep.

**Figure 1.** Firstbeat report used in data interpretation.



The physiological assumptions on which the Firstbeat summary is based rely on certain algorithms and therefore cannot be considered absolute in any way. A physician who has studied Firstbeat measurements provided the following instructions:

In the case of people who do creative work, experts, managers, *etc.*, it is essential that a high activity level (work flow) be distinguishable from harmful stress. Both often show as red, for almost all waking hours. Other analyses must be used too, and these are offered by the Firstbeat method: a diary, questionnaires, or other indicators altogether. For the physical side of things, it must be noted that, for example, a walk may not be registered as a physically active period for people who are in good shape. There are also differences between individuals. The status of the autonomic nervous system changes rapidly for some people. They react quickly, but the operation of their central nervous system is not more stressed, even if the indicator seems to show that it is. [26]

Data visualizations do not stand in a one-to-one illustrative relation to the empirical world: crafting an image is a historically defined practice that relies on a combination of technical, literary and social skills [4] (p. 8). Because of the many possible interpretations allowed by the visualizations, it was important that they were not simply passed on to the participants. We arranged coaching sessions, with five to eight participants in each,<sup>2</sup> in which the participants were

<sup>2</sup> The coaching sessions were designed with Tuula Styman, who has used Firstbeat reports in wellbeing coaching. She was also in charge of the sessions, so the role of the researchers at this point was participatory rather than instructive.



given background information about Firstbeat reports; the idea was to make it more transparent that self-tracking devices are abstracting physical reactions into data flows and visualizations by following certain conventions and assumptions. For instance, it is a convention that stress is visualized as red and recovery green. Moreover, the images representing physiological stress and recovery simplify and summarize the subjects' everyday life on the basis of certain technical assumptions.

The coaching part of this research, utilizing Firstbeat reports, shares features with the ethno-mining used for cultural analysis [27] that combines the collection and analysis of quantitative data with that of qualitative data in an iterative framework. The data visualizations operate as shared artifacts for co-constructing and negotiating meaning; the reports are not treated as factual accounts of stress and recovery but as part of knowledge creation and crafting research findings in collaboration. The charts bring insights to the surface in people's lives; they serve as mediators and translators in the sense that they feed forward discussions and negotiations rather than offering a transparent vista of people's bodily reactions, or their daily lives.

Significantly, self-monitoring is not only about capturing data flows and transforming the body into information; it also feeds this information back to people in a visual format, enabling and promoting emotional attachments and intensifying them [5] (p. 237). Once visualized, the data generates new kinds of affective ties between people and their measured actions and reactions [23,28]. For instance, pedometer users can cherish the steps they have taken and develop a more affective relationship either to their walking or the steps taken; numbers acquire qualities that promote new kinds of walking-related practices [11] (p. 50). Similarly, the monitoring of the quality of sleep through heart-rate variability measurements can deepen affective relations to one's body. When sleeping is subjected to tracking, it becomes an activity, or even a competence, that people feel that they are good at. On the other hand, the tired body, pinned down by personal analytics, reflects exhaustion caused by the energy that people put into work and care for others, thereby making their contributions visible and of value.

In the coaching sessions, people recognized their days from the reports, and found satisfactory explanations for the stress peaks and recoveries depicted in the images. Most of them also had diary entries to support the reports: one of the women noticed that, in her case, hovering promoted physiological recovery. The data visualizations can "upgrade" everyday doings and underline the fact that people weigh up the value that they give to the curves depicting stress and recovery. Work around the house gains a new kind of importance by being a source of physiological recovery. In other words, remedial moments at home and during the working day are appreciated in a new way: snacks by the computer, a shared coffee break with co-workers, messaging on Facebook. Insights such as these emphasize the fact that engagements with data doubles can encourage the detection of something new and unexpected in permanence, in the way things are. Such observations were typically mundane, but they provoked discussion and evoked emotional responses. Significantly, data visualizations were interpreted by research participants as more "factual" or "credible" insights into their daily lives than their subjective experiences. This intertwines with the deeply-rooted cultural notion that "seeing" makes knowledge reliable and trustworthy [29].

Sometimes the details that people desired were not found in the data visualization, though they might find something else. One of the participants regretted that he caught a cold during the study period and could not exercise to see how it affected his physiological stress and recovery. Instead, he found that the curves were informative about the course of his working days. He noticed that his stress level decreased over lunch and that he recovered physiologically in the afternoon as the office was getting emptier. In a later telephone conversation, he said that he had changed his schedule so that he now goes to work earlier, starting work before eight in the morning. This way, he felt, he might be able to avoid some stress during the work day.

The coaching sessions suggested that data doubles create emotional and practical involvements: they represent something to which people can try to respond. However, not all information supplied by the curves was equally unambiguous; they also provided data that people could not explain. For example, one of the men was surprised to find that he did not relax in the evening. He wondered whether his late-night stress peaks were due to the onset of a cold or to watching television, but he could not find a satisfying answer. The white areas in the reports—the measurements between stress peaks and recovery periods—also provoked lively conversation. The subjects found white areas in their curves occurring during telephone conversations, meditation, art-gallery visits, play with children, and wind-down after exercise. Meaningful things for them seemed to be happening in the white areas. Somewhat disappointingly, explanations related to the measurement technology could also be found for these events. For instance, during yoga, the control of breathing may cause “abnormal” synchronization of heartbeat and breathing; the application cannot analyze the heart-rate variation, which shows up as a white area in the report. White areas can also result if the electrode is too loosely attached, the subject has muscle tension in the chest area that hinders sensing of the weak electrical current from the heart, or extrasystoles. Analyses based on heart-rate variations assume that the heartbeat is regular (sinus rhythm). In reality, even the hearts of healthy individuals exhibit extra beats of various kinds, and the computer is unable to identify all of them [20]. Failures of technology were treated as a nuisance, but they did not erode the research participant’s desire to trust the data. Instead, many participants concluded that they wanted another round of measurements in order to produce better data. The data were giving important clues, but too much of life appeared to be taking place outside of the data flows. In order to gain a clearer vision of the things that matter, people longed for more tracking and supporting evidence for the curves depicted in the reports.

## **6. Making Sense of Recovery**

The second study round aimed at deepening understanding of how people confront their data by making explicit how participants could learn and benefit from the data collection and analysis. The aim was to explore uses of data that might point towards formerly hidden possibilities and directions, and demonstrate, for instance, how the data allow the reevaluation of “the personal” or “the everyday”. We asked one of the participants from the first round, a 30-year-old father of small children, to take part in the instruction session: he gave a visual presentation on his own results and explained what knowledge and insights he had obtained from engagements with his data with the support of a detailed journal of daily activities. Summarizing his experiences in an inspiring

manner, he explained what he had discovered about his daily rhythms, exercise, and alcohol consumption. In addition, he described how surprised he was to find that his physiology might not have been in sync with his expectations: for instance, spending time with a small child could feel stressful but be physiologically a way to recover.

As before, the data reports were discussed in coaching sessions that were followed by individual interviews. The coaching sessions were voluntary and a couple of research participants did not join them, highlighting the fact that even in a self-tracking experiment such as ours, where people volunteered to take part, data-enthusiasm was counter-balanced by data-indifference. In the sessions, recovery periods, places, and techniques were identified from the data. Although the research subjects were reminded that each individual is different in physiological terms and they should not compare their reports directly with those of others, comparisons interested them. Plentiful recovery was admired: a recurrent theme of conversations was how daily life could be made more balanced. Time and again the research participants focused on the fact that, in light of physiological data, daily activities that were found to coincide with physiological recovery were everyday chores: mangling, folding laundry, fixing a bicycle, and doing handicrafts. Activities that promoted recovery also included telephone conversations with one's mother, reading a bedtime story to children, and a successful meeting at work.

The purpose of individual interviews was to deepen the insights gained in coaching sessions, to go over the course of the tracked day, and discuss and evaluate it in light of the measurement data. Particular attention was paid to exceptional events and surprising outcomes in the data. The interviews unfolded according to how deeply into their results the research participants were prepared to go, a reminder of the private nature of personal data. A few subjects did not want to discuss their daily events and physiological reactions with the researcher in great detail, nor had everyone written journals. Some had no visible interest in their personal data and preferred a more general discussion, focusing on the future of self-tracking technologies, or the philosophy of happiness, for instance. Most participants had, however, detailed journal entries that they wanted to share; they were enthusiastic about the possibility of engaging with their data.

Some research participants might have been concerned before getting the results, though upon seeing the data they felt relieved. "I don't need to be that worried," as one of the men put it. One of the younger women was happy to see that she was active during the day. "I am not exactly a couch potato", she happily concluded at the end of her lengthy inspection of the visualized data. Another woman said she had been nervous about the feedback session, because she had been scared about discovering the degree of stress her work entailed. The measurements did, in fact, support her claims of tensions experienced at work. In the interview, she explained the history of a complicated relationship with her supervisor. She had suffered stress-related physical symptoms, such as headaches and stomach pain and, because of these, she had actively tried to avoid her supervisor by scheduling her work for times when the supervisor was not in the office. The concrete presentation of her irritation in visual form, however, forced her to think about the issue:

I clash with my closest supervisor. His behavior is annoying. The measurements prove that I'm stressed when I'm in contact with him. I wonder what the coping strategies available to me are. There is no sense in my changing jobs at this point. There must be

another way. I react strongly, which requires thinking about. How will I arrange my work? (Interview, [30])

Physiological reactions cannot be separated from social relations, even if people wish they could be. The visualizations suggest that co-workers and supervisors generate stress. If one decides to continue working in the same workplace, one way of avoiding stress is to avoid the unpleasant person. Similarly, quarrels or tensions at home are stressful in light of measurement results. That said, the tantrums of small children and rows with a spouse seemed to cause surprisingly little stress, according to the data. Taking a child to a day-care center may feel stressful, but the measurement data that allow research participants to examine their lives seem to point to it as not exceptionally so. This visibility led to an attention to stress-free doing and being. From this perspective, personal analytics can increase understanding about the importance of doing things that require no particular effort. It can make waiting, resting, and daily routines recognized and even valued: in terms of physiological recovery, “useless” activities gain a new kind of value by becoming physiologically beneficial. Such observations on data flows generated discussions about the nature of stress and stressful situations, meanwhile highlighting cultural uncertainty over stress that indicates that the self-monitoring data actualizes relations and connections that are beyond common ways of perceiving, knowing, and responding to things. Despite decades of research, little is known of the way in which bodies, minds, and socialities co-constitute stress [31,32]. While the measurement opens new vistas onto people’s lives, it calls for a rethinking of the elements of which those lives are thought to consist. This can lead to the questioning of concepts, such as stress, that are often taken for granted. Rather than a straightforward project of producing conditions for healthier lives through self-tracking, the engagements with data doubles generate various kinds of ideas of one’s behavior with and in relation to others, including those that can challenge existing expertise on health and wellbeing.

## **7. A Slice of Larger Life**

As personal analytics becomes more commonplace in homes, schools and workplaces, questions of how and for what purposes self-monitoring data could and should be used become timely. With the aid of self-tracking devices, everyday processes are translated into information. Everyday life—its entities, relationships and processes—are not only captured and represented in abstract graphs, tables and figures, but become negotiable and actionable. From the perspective of people’s engagements with their data doubles the fact that self-tracking devices and data flows connect to and mediate self-knowledge is crucial. Knowing becomes inseparable from the data visualizations; smartphone applications and other monitoring devices act as mediators and translators that contribute to making human reactions and life visible, identifiable and knowable. Similarly to gene maps and brain scans, the visualizations produced by heart-rate variation measurements provoke discussions and negotiations surrounding the value and meaning of the images, rather than providing unambiguous answers and a transparent window onto the individual [8,23]. Tracking technologies tell partial stories of much larger lives [27] (p. 10).

Data doubles are contemporary images, combining existing knowledge and skills, but they also promote new kinds of practices and skills related to data. By enabling interactions and engagements with people and their data doubles, our research demonstrates how data doubles can provoke and activate an awareness of the body and the everyday, also providing possibilities for the enhancement and improvement of life. The interpretation of measurement data, in an open-ended and iterative framework, creates a participatory space that focuses on crafting research findings in collaboration. Interpreting measurement data jointly with others (in this case, with other participants in the study, researchers, and a hired coach) allows the research findings to build on and resonate with people's self-understanding and aspirations. Engagements with data doubles illustrate the desire to enhance and improve daily lives: in our study people treated personal analytics as a resource that could aid in learning about and forming practices contributing to the achievement of a "fulfilled life". At the same time, self-tracking was approached with curiosity; people expected to be entertained and surprised by the research findings and they wanted to learn new and unexpected things about themselves and others.

The indicators and measurements ultimately affect the measured, including the objects of measurements and the ways the measured is valued (e.g., [23]). When people use measuring devices to "prove" that massage or reflexology has health benefits alongside medication, or make visible the physiological impacts of idle moments, art, caring for others, or alternative therapies, their testimonies can gain new weight. Self-tracking technologies can open new routes to health and well-being. Not all of our research participants, however, were equally excited or convinced about such data-led possibilities. For some the idea of extracting knowledge from data flows was ultimately not appealing; it was thought that it offered too individualistic and constraining a window onto everyday lives. The refusal or lack of enthusiasm of this group to engage with data doubles is a reminder of the fact that personal analytics is by no means a universally attractive way to explore the previously inaccessible. Yet based on our findings, self-monitoring devices are encapsulating the technical and the conceptual in a manner that will continue to appeal to people, and generate new kinds of data engagements focusing on the self and social relations. Self-tracking can be used for generating surveillance that probes ever more deeply into what it is to know and be human, increasing the potential for greater control over one's life. Control, however, also provokes protest, a desire to act unexpectedly. Self-tracking devices teach people to encounter, use and interpret data for purposes that go beyond the data.

## **8. Conclusions**

This article has approached specific data engagements by emphasizing the device-precise ways in which data is generated and visualized. Tracking devices are individualistic in their orientation, solidifying existing economic and political divides: self-monitoring is spreading among those who have the skills and means to connect to their bodies, minds and lives in data-driven ways. On the other hand, they promote new frameworks for approaching normalities and pathologies in daily lives. A powerful aspect of self-tracking tools is their ability to mediate the reimagining of the present. For instance, phenomena that are considered discrete, such as addiction and use of time, can be examined within a shared frame; addictions can be treated as a problem of time use rather

than as individual pathologies [33]. Thus a stimulating aspect of self-tracking technology that can aid social research is the possibility it provides of transcending juxtapositions of the biological and the social: the mind and the body, and the normal and the pathological interweave when everyday actions and physiological reactions are described within the same research design. Here, studies benefiting from self-tracking can build on and continue the long history of research into making bodily experiences visible through a phenomenological research approach that describes personal knowledge obtained through the body [34]. Self-tracking can add to this research tradition by identifying and classifying physiological and bodily data that would be difficult, or even impossible, to obtain otherwise [35]. Although a research design that uses self-tracking devices does not promise a direct or unambiguous access to the personal or the individual, it does represent data on bodily reactions in a thought-provoking manner.

A huge amount of energy is currently invested in developing self-monitoring devices and applications [2] that compete with each other for their role as data centers in people's lives. A study such as ours demonstrates some aspects of the allure of data-led everyday lives. The playfulness and creativity of people interacting with measuring devices suggests that tracking promotes "numerical living" that can be fun and engaging. Another area of research arises from the fact that people are actively using personal data for framing social wholes and entities, giving a new kind of value to their personal realities and everyday doings. The manner in which data streams are being worked and reworked suggest explanations that can produce permanence and stability, but can also profoundly change ways in which people reflect on themselves, others and their daily lives. Important in terms of future research on data doubles is the social life of data, including ways in which self-tracking data is recognized, appreciated, affirmed and harnessed to various kinds of purposes. These tie in with how specific monitoring devices shape assumptions and promises of visibility and knowing, further connecting to research on how digital devices and the data that they generate configure knowledge spaces in society and the social sciences [10].

## Acknowledgements

I am grateful to my colleagues Mika Pantzar and Veera Mustonen without whom this article would not have been possible. In addition, I thank Marie-Louise Karttunen and Joni Kettunen. The study was supported by the SalWe Research Program for Mind and Body (Tekes—the Finnish Funding Agency for Technology and Innovation grant 1104/10).

## Conflicts of Interest

The author declares no conflict of interest.

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# The Touch Pad Body: A Generative Transcultural Digital Device Interrupting Received Ideas and Practices in Aboriginal Health

Michael Christie and Helen Verran

**Abstract:** Yolŋu Aboriginal understandings of the body, health, life and sickness, and roles their ancestral epistemologies and knowledge practices play in making agreement have seldom been taken seriously in the biomedical world. In this paper, we describe how insights developed in three different cross-cultural collaborative transdisciplinary research projects led to the design of a digital device aimed at intervening in communicative practices around body, health, life and sickness, interrupting the received practices and assumptions on both sides of the practitioner-client divide. The interrupting device slows down and opens up communication practices potentially leading to mutual understanding, collective agreement making, and bottom-up changes in remote Aboriginal health policy and practice.

Reprinted from *Societies*. Cite as: Christie, M.; Verran, H. The Touch Pad Body: A Generative Transcultural Digital Device Interrupting Received Ideas and Practices in Aboriginal Health. *Societies* **2014**, *4*, 2566264.

## 1. Introduction

The subject of this paper is a digital device for use in those times and places where health professionals and Aboriginal patients and their families are struggling to go on together in generating plans and collective proceedings to achieve healthier Aboriginal individuals, families, and communities. The device is an iPad or generic custom-designed touch screen application that shows interactive biomedical images, animations and models. We propose that this application will differ from other similar applications in that it will not embed any explicit health messages (it is not didactic); it will not privilege the biomedical model of the human body and its functioning; it will not contain any microscopic scale imagery, and will contain few sequential arrays of images. The device will depend entirely upon users in conversation for its navigational logic and focus first on aspects of the healthy body, only later introducing pathology in leading up to images of the experience of chronic disease and its treatment. The design of the device is inspired by Yolŋu principles of communication that we have gradually learned through our participation in other health related projects. In this paper we first elaborate what we understand those principles of communication to be in telling stories of the contexts in which we learned them. Then in our final section we explain how these principles are expressed in the design of the Touch Pad Body. However, we need to be clear in beginning, that this device has reached the concept prototype stage only. At this point we have been unable to secure funding to actually build the device.

## 2. Knowledge and Agreement Making in Arnhem Land

The Yolŋu Aboriginal people of northeast Arnhem Land, Australia have a long tradition of theorizing about knowledge production, conflict resolution and agreement making [1–3]. When bilingual education was introduced to three major Yolŋu schools in the early 1970s, a long process of mobilizing ancestral theory to inform curriculum and pedagogy began. As a young teacher in 1973 Michael was already a keen language learner when invited to become a teacher linguist, and to work with Yolŋu knowledge authorities on research and literature production. Helen became involved in 1987 when she found herself working with the Yirrkala School community under a program of “Aboriginalisation” of the school supported by both the Yolngu elders and the Department of Education. In particular, as a university lecturer in mathematics education she was involved in “both ways” or “Garma Maths” curriculum development. Over the succeeding 40 years, we have been involved in collaborative research and consultancy work which has extended the reach of Yolŋu practices into much other work—including law, housing [4], financial literacy [5], water management [6], community gardening [7], and digital knowledge work [8]. The particularly difficult process of devising a digital “interrupting tool” to embed these agreement making practices into the world of remote Aboriginal health is the subject of this paper.

The curriculum instituted by Yolŋu community elders at the Yirrkala Community School was given the name of *garma*. In Yolŋu languages, *garma* refers to an open public ceremonial space where people from different tribal and totemic lineages come together to produce a collaborative performance and celebration of history, and a collective agreement on ways forward, here and now. The *garma* “describes the format where a Yolŋu learning environment begins” [9]. The *garma* (like Aboriginal education and transdisciplinary research) actually depends on identifying, respecting and maintaining differences, working collaboratively, coming to agreement, and building agreed ways of knowing and going ahead together [10,11].

All *garma* performances start off with an issue, be it a funeral or an initiation or maybe the return of a sacred object to its maker’s descendants. They all entail a common purpose, and a claim of authority. While each group has a large repertoire of songs, dances, gestures, paintings and paraphernalia which can be presented alongside others who share parts of ancestral histories, journeys and totems, they collaborate to choose carefully which songs (dances, names, gestures, paintings, totemic objects) will be shared in this particular located *garma*, and how, while playing out with other clans their collective history, they will also enact their own distinctive perspective with their own authority in the work around this particular issue, here and now. Having the right people in the right space together under the right authority is always critical to the work of making agreement. Any individual, no matter how specialist, how expert, cannot decide the best way forward alone. This robust Yolŋu epistemology keeps resurfacing in our work. Here, we tell of three distinct research projects from which the conception of the touch pad digital device draws inspiration.

### 3. Sharing the True Stories

By the 1990s, many Yolŋu who had been curriculum activists in Yolŋu schools were becoming active in other research fields. This work involved a woman who was in her own right a Yolŋu knowledge authority, an experienced Yolŋu educator and linguist, who had had to move from her remote island home to the city of Darwin for dialysis. She became involved in advocacy for better communication between medical practitioners and their renal patients. As a linguist I (the first author) was invited to help with a research project aimed at identifying and rectifying common causes of miscommunication [12]. Yolŋu medical patients, especially those with serious chronic diseases, were often suspicious that they weren't being told the true story about their illness. They were also convinced that their own stories were not being taken seriously by the medical staff. While she was only one of a large group of mostly white Australian researchers, this senior Yolŋu woman convinced us pretty early to call the whole project "Sharing the True Stories" (STTS). She flatly repudiated the simplistic conduit metaphor [13] which sustained the illusion (so common in western understandings of communication) that messages are somehow passed from one person to another as if along a conduit.

We were required to rethink communication as the building of shared understandings, and as the research project developed we were often amused and bemused at how often the non-Aboriginal researchers and workers on the renal floor reverted to the conduit metaphor when describing their work and their frustrations to us. Through her own quiet contributions to the project, this authoritative woman, speaking out of her experiences as a Yolŋu patient, showed us the key role of narratives and of conversations which we were later to take with us into the work of designing digital resources. One key outcome of the project deriving from the Yolŋu theory of communication was increased attention to all the work which is done outside of the clinical encounter, leading us to move away from the clinical encounter as the key locus of information sharing and agreement making. The burden of communication in the clinical encounter—even with an interpreter, is intolerable. While we worked to improve the work of engagement of interpreters, we also concentrated on other things not immediately obvious as relevant to communication.

For example, a major outcome implemented in Stage 2 of the STTS project involved group meetings around clinical encounters. Honest good-faith agreement upon often quite unusual, specific ways forward for a particular patient involved something of a *garma*: a meeting together of as many different experts as possible, nephrologists, dietitians, renal nurses, general practitioners, social workers, as well as husbands, mothers, children friends, other patients from the same language group. Moreover, as our senior Yolŋu colleague pointed out, the configurations of people and spaces, charts and instruments also contribute to the *garma*, as does, of course, the patient, the real expert on the body in question.

Almost unbeknownst to us, the Yolŋu researchers were leading us to understand and undertake health communication in different ways, and these different ways needed to be taken seriously and understood and acted upon collectively, if we were to make a lasting difference to patient and community outcomes. (How those productive advances instituted in the renal unit were ultimately slowly worn down by bureaucratic demands must be the subject of another paper.) We were not at the stage of concentrating on developing a more general theory of health literacy, but are focusing

on particular sites where health literacy comes into play (see below). However, our first step had been to engage an Yolŋu epistemology.

#### **4. Healthy Breathing and Heart**

Our digital device emerged also from outside the careful Yolŋu analysis of agreement making. We were invited some years later by a senior thoracic surgeon from a large southern teaching hospital, to help him review a suite of disparate digital resources which had been produced to inform people about ‘healthy breathing and hearts’. He had hundreds of images and animations which he showed to a sometimes bored, sometimes startled, sometimes fascinated and animated, often irritated group of senior bilingual Yolŋu consultants over several days. His aim was to produce the perfect health literacy tool to inform Aboriginal patients whose first language is not English, and who may not be comfortable talking about intimate bodily things in an unfamiliar tongue, about lungs, hearts, circulation and of course, smoking [14]. There were a few problems. From the beginning there were many images, particularly those which showed microscopic details which were simply incomprehensible. I could see that the taken for granted conventions for representing movement, scale, and three dimensionality, for example, in our western graphic traditions were often not coming across at all. It never occurred to the Yolŋu consultants, always looking for a chance to build shared understandings in good faith, to say they had no idea what they were looking at. Like patients in the Sharing the True Stories research, when they didn’t understand something they smiled and nodded agreeably in the face of authority, waiting for something to make sense. What did make sense to them was the top-down disciplinary nature of much of what they were asked to review. It seemed to be blaming them and others for making bad life decisions without ever giving them a chance to contribute their own opinions. It was hard for them to have a reasonable conversation with the thoracic surgeon, despite him being gentle, generous and deeply concerned about Indigenous health. He was completely disconcerted that the photos of diseased organs were offensive, and to hear how wrong it is to say to a patient that there is a chance that the lump they have presented could be a cancer. That is an offensive way to talk. The doctor should say “If you are worried about that lump, we can do some tests and find out what’s going on there”. How conversations produce symptoms was quite lost on the doctor who didn’t understand the ways in which collective Aboriginal performances produce new possible worlds. We must therefore be careful how we perform in a collective agreement making episode.

The outcome of the consultancy was, alas, further production of another top down disciplinary digital resource, but that is another story. The conversations we had around how to talk to the owner of an Aboriginal body led us still further towards a culturally sensitive technology.

#### **5. Redefining Health Literacy**

In the third research project we were asked with our Yolŋu colleagues, to evaluate needs for health literacy, health communication and interpreters in east Arnhem Land. In the East Arnhem Region Aboriginal Client Health Education (EARACHE) project, we interviewed over 50 community members from five different communities in their own languages, and held extensive discussion

with another 50 health professionals [15]. We found many different roles and job titles—infant health workers, general practitioners, Aboriginal health workers, mental health workers, community health workers, ear health, *etc.*) and a vast array of health communication resources—digital and on paper—were mostly unused. This was seen against the background of several distinct languages and several distinct cultures, *i.e.*, Aboriginal community life, the culture of small clinic health service delivery, and plural government bureaucracies. The people we interviewed were tired of researchers coming to troubleshoot the system, tired of the overwhelming and increasingly differentiated health work force, and tired of the top-down disciplinary health literacy messages. However, we also heard so many stories of unusual, highly productive collaborations across boundaries of professional responsibility and across the boundaries of culture which were invisible from above, unsupported, but carried out through long conversations with commitment and good faith and good results.

Good health literacy, we concluded, especially in this remote Aboriginal context of extended family and community living, is better understood not so much as what the individual client knows about biomedicine, but rather the productive working together of the people and resources which generate shared understandings and agreement. It involves good access to clear information, and honest respectful discussion and agreement making across the divide between providers and consumers. Health literacy is not so much a knowledge problem as a structural problem so there are structural solutions. We began to talk of “systemic health literacy”. Present attempts to improve Aboriginal health communication practices and “health literacy” tend to utilize a top-down policy approach which seem to blame the client for irresponsible life choices and ways, and/or front line workers for poor delivery. Yet health professionals, clients and families were often using their discretion to create good open collaborative ways of working together. How could we support this work?

We came to understand “policy” as the cumulative effect of the individual decisions made by front line workers producing slow but effective and evidence-based bottom-up changes to practice [16]. We found Aboriginal and non-Aboriginal people discerning what is working on the ground, supporting it, having conversations around difficult decisions about chronic diseases, and making informed decisions together. We also found that resources that contain health messages seldom stimulated these productive conversations which promote new productive collaborations across the boundaries between health professionals, service users and their families. On the contrary, they actually tended to entrench definitions, roles and attitudes rather than modify them.

So in the EARACHE project we sought to develop strategies consistent with the knowledge and agreement practices we had developed with our Yolŋu co-researchers in STTS. Aboriginal clients have strong ideas and practices of embodiment and well being which might be quite different from those in other constructions, say of policy makers or health professionals or interpreters. Received views of agency in the rhetoric around health literacy infect our ability to offer alternative strategies for improved practices. We attend to the agency of these health communication resources.

## 6. The Touch Pad Interrupting Tool

A collective approach to dealing with the problems of the moment allows us to remain respectful of both government and Aboriginal community members and the participants in their worlds—even though they may be quite different. A collective approach allows us to avoid assuming the salience of the biomedical model, as well as the individualism of western ethics and political philosophies. There are many good health literacy resources out there, and we will encourage their use, but we propose a different sort of object which we have designed in the process of the HBH research project.

We propose a radically different resource, a user-friendly touch-pad animation of a diagrammed human body which has no message, no sequence. It is manipulable, zoomable, transparent, three dimensional, detailed in particular areas (heart, lungs, kidneys, liver, pancreas, ears). Such bodily structures are familiar to patients and their families and to health professionals, albeit in different ways. The diagramming of the Touch Pad Body de-emphasises biomedical details and assumptions. It stimulates conversation—in any language or mixture of languages. The conversations which the interactive diagram generates will not be unlike the conversations through which it is iteratively developed. Designed collaboratively, its development and its use will be coterminous. Which parts it shows and which it conceals, its genders and its pathologies will all be designed and developed collaboratively so it emerges as a body which is both Aboriginal and biomedical emergent in exchange in particular times and places.

So how does this device embody the principles of communication we have learned from our Yolŋu colleagues in a number of projects across several years? The device promotes a sharing of the burden, and a continuation of the so called “phatic” elements of communication. This is the work done by such utterances as “Hello. How are you?” It is the work of promoting sociability in which mutually engaging communication can occur. The device in part provides a form of diagrammatic infrastructure to enables that phatic work to continue and importantly to be done on all sides, so that it is not only Aboriginal patients who find themselves doing all the work. However, more substantively, when it comes to human bodies the device works at a level “below” the ontological, and the emergent diagram it provides is not a representation of a determining structure.

As itself an emerging body in the here and now of the clinical encounter—albeit of a very different corporeality than a flesh and blood human body, the diagram will interrupt the presumptions of all contributing parties presuming “neither biomedical certainties, nor Aboriginal certainties about bodies” [17]. By using the device as a diagram to pilot a conversation around the individual problem of the moment, accepting the constraints of that particular here and now, and not obliged to import and to promote “theories about bodies” formulated in other times and places which may or may not be salient to the issues at hand, the device evades a priori assumptions at work in the working stories of all these different participants (the biomedics, the Aboriginal patients, the social workers, family members, *etc.*), which entrench received assumptions, and prevent us from thinking and acting together in new ways.

The Touch Pad Body will likely split into various versions, with the possibilities of adding family members and environments, as they suffer when individuals suffer and take part in

treatment and healing. Some version may find its way into schools, or to the training of health workers and interpreters [18]. However, by its very ambiguity, its capacity to absorb contradictions and tread the tight-rope of equivocation it will always open up the opportunity to interrupt the assumptions of strangeness or certitude at work between the Aboriginal and the biomedical.

In the EARACHE project it was clearly impossible for us to recommend any top down structural changes to health literacy projects which would guarantee a direct improvement on the health literacy of 7000 people. However, we did recommend the support of flexible collective ground-level discretion and decision making wherever there is openness and interest to start the conversation going, and to join up existing individuals and services. Our Touch Pad Body can actively stimulate this work, particularly by making itself an essential, well known public resource, (through making its images available more widely through posters, websites, leaflets, *etc.*) and by its very ubiquity it could institutionalize collective agreement making over medical issues, marginalize the autocratic practitioners including some of the fly-in fly-out specialists, and cry out for a *garma*-style setting which activates complex intercultural conversation to generate a unique complex way forward for this medical issue here and now. Moreover, those using it would be part of the collective iterative design, development, implementation and evaluation project. Our device interrupts received notions and entrenched practices by getting as many authoritative people talking about each medical decision in their own way, but together. Our yet unfunded, undeveloped digital device will help this bottom-up change in mutual understanding, agreement making and informed consent to reverberate upwards towards changing policies and practices at higher levels. We look forward to working with this device, when funds are made available to bring it fully to life. There are issues associated with its interventions that can only be dealt with ‘face-to-face’ with the device, so to speak. How can we contrive the routines and the techniques by which agreement over how to build agreement in ways that explicitly involve humans and non-humans actively contributing? In particular where and how might the important principle of informed consent be given its due?

In all this piecemeal work, our digital *garma* device will promote a new coherence and reflexivity in the ways in which service users and providers approach their work with Aboriginal patients and their families. Real change comes when categories are unsettled, where we have conversations which allow us all to rethink our assumptions and our collective possibilities. Finding new ways of understanding and enhancing health literacy requires using the language and tools available for developing a generative health literacy policy and practice, first of all at the local level. Both Aboriginal people and governments could be “end users” of research, providing an evidence base, which should not be different from making policy change.

## 7. Conclusions

Yolngu Aboriginal principles of communication have been conveyed in telling stories out of our experiences of participating in health related research projects under the tutelage of senior Aboriginal people, often themselves clients of health delivery services. Acting on this gradually developed understanding of Yolngu experience and expectations of how the clinical experience should proceed, we have worked with designers to develop an electronic communication device that interrupts the normal clinical encounter. The device elicits phatic contributions from both

clinical personnel and Aboriginal clients; exchanges that attend to the important work of maintaining the sociability of the encounter. In addition it deflects the precise clinical observations and prescriptions of health professionals away from what is experienced as unwarranted and unacceptable imagined intrusions into actual patient bodies, to instead become expressions of concern for the Touch Pad Body generated in the encounter, as an intimate, interactive ‘stand-in’ for the patient’s body. This enables, as a subsequent distinct step, informed delicate negotiations over agreement to responsibly accept medical interventions. This device currently exists as a concept prototype as we are yet to secure funds to take the device to a further stage.

### **Acknowledgements**

We acknowledge the many Yolŋu knowledge authorities who have helped us understand our work over many years. Sharing the True Stories was funded by the CRC for Aboriginal Health. Healthy Breathing and Heart was funded by the Institute for Breathing and Sleep, Austin Hospital. The East Arnhem Health Literacy project was funded by the Australian Office for Aboriginal and Torres Strait Islander Health. Betty Marrŋanyin, and Anne Lowell were key researchers in STTS. Yiŋiya Guyula, Dhaŋgal Gurruwiwi, Janice Munhdhu, Waymamba Gaykamaŋu, and Joanne Garŋgulkpuy were consultants on the HBH project working with John Greatorex and Christian Clark. Juli Cathcart and Trevor van Weeren coordinated many workers on the EARACHE project and designed the proof of concept for the Touch Pad Body.

### **Author Contributions**

Michael Christie was a chief investigator in all the research projects outlined here. Helen Verran and Michael Christie have worked with the Yolŋu Aboriginal Consultancy Initiative researchers and consultants helping to understand the complex issues of working knowledge practices together in a variety of settings. See [cdu.edu.au/yaci](http://cdu.edu.au/yaci).

### **Conflicts of Interest**

The authors declare no conflict of interest.

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# Understanding Digital Health as Public Pedagogy: A Critical Framework

Emma Rich and Andy Miah

**Abstract:** This paper argues on behalf of a public pedagogy approach to developing a critical understanding of digital health technologies. It begins by appraising the hitherto polarised articulations of digital innovation as either techno-utopian or techno-dystopian, examining these expectations of technology and considering the tensions between them. It subsequently outlines how a public pedagogy approach can help mediate between these views, offering a more contextualised, socio-political perspective of mHealth. This approach teases out the nuances of digital health by engaging with the complexities of embodied learning. Furthermore, it urges caution against viewing these pedagogical forces as one of transference, or simple governance. To this end, we therefore contextualise our critique of digital health, within an attempt to reconstitute an understanding of public pedagogies of technology.

Reprinted from *Societies*. Cite as: Rich, E.; Miah, A. Understanding Digital Health as Public Pedagogy: A Critical Framework. *Societies* **2014**, *4*, 2966315.

## 1. Introduction

In recent years, the surveillance of people's lives, bodies and health has been accentuated by the proliferation of digital systems and, in particular, the development of Internet-based technologies, which have significantly changed the way people engage with the data that surrounds their lives. The range of digital tools available is broad and a considerable amount of research has taken place to study how people negotiate their health in digital spaces, most apparent within the archives of the *Journal of Medical Internet Research*.

For many years, the focus of cybermedical encounters was on interactions that take place through websites and the wider impact of computer culture. Within this body of work, there was a tendency to engage with discourses of the utopian or dystopian consequences that may arise from an increasingly digital society. The Internet was considered to be a place that had the potential to change society in fundamental ways. In the case of the utopian expectations, early studies about the Internet wrote of how it would revolutionise society, breaking down social barriers and making the world a better place. Research focused on structure and inter-personal dimensions, which would free people from burdens associated with the physical world, such as the constraints of image and identity [1,2]. Such prospects led some researchers to advocate the alteration or elimination of bodies as a desirable future for humanity [3,4]. The *obsolete body* was thus seen as the manifestation of a techno-utopia.

In the context of health care, these expectations were reinforced by views that foresaw the capacity of digital technology to create a more cost-effective way of delivering health care. Moreover, the proliferation of digital technologies across all sectors of society would lead to an increased utilization of and reliance upon digital solutions within the healthcare sector. Emerging

out of an era of telemedicine and, later, discourses around “cybermedicine” and mobile health [5], the appeal of digital solutions occurred against a backdrop of welfare cuts, rising health care concerns about the global increase in “lifestyle” diseases such as obesity. In this sense, digital health—as a focus for policy investments—flourishes as a result of its capacity to generate greater efficiencies within an already overburdened system. Integral to this utopian discourse on cybermedicine’s capacity to revolutionize healthcare, a further discourse has developed that focuses on how digital technology could radically alter the quality of provision and better reinforce some of the ethical aspirations of medicine. For instance, researchers wrote about how health care could promote patient autonomy and professional accountability [6,7]. In this sense, digital health was not just a way of delivering more efficient care, but better quality care as well.

In contrast, among the public discourse on this brave new virtual world were anxieties about how it would lead to more disenfranchised, lonely individuals, with diminished social skills and, potentially, dispositions that would be bordering on clinically alarming, addiction to cyberspace being a commonly expressed concern. Such dystopian views were articulated in relation to video game culture, framed by a similar kind of moral panic that has surrounded other new media forms, such as certain genres of popular music, or film. Thus, the Internet was seen as a place where bad things happen to otherwise good people. These views have been re-articulated with each new innovation online, from social media to wearable technology [8,9]. For instance, neuroscientist Susan Greenfield is frequently given space in the media to warn people of virtual worlds, claiming that too much time online can even be detrimental to processes within the brain [10].

As web studies emerged more formally in the late 1990s, and as more rigorous methodological approaches developed for analysing what takes place online [11], less attention was given to the long term transformative dimensions of the Internet, and more focus was placed on what was actually taking place online. As a result, the research community of digital studies scholars fragmented very early on in the development of this new thematic area and this fracturing makes it difficult to assert that there was a single techno-utopian vision of cyberspace that was envisioned for health care. Equally, policy debates focused more on the instrumental benefits of telemedicine and their parameters were far narrower than imagining anything as grand as utopia. Indeed, too much digital health was seen as antithetical to utopia, at least in terms of governance. The rise and fall of Google Health evidences the limitations of digital health interventions aimed at transferring responsibility wholly to the individual away from the state.

In this context, our initial critical reaction to discourses on digital health is to deny that there was ever a sufficiently wide perspective on the prospects of digital health to warrant its being described as a techno-utopian project. Instead, there were instrumental aspirations around promoting digital health, which were about governance and, to some extent, ethics. However, there was no wider moral framework in which these aspirations for health care were situated. Thus, if a utopia—in the commonly employed sense of the term—may be used to describe a state of perfection, then the instrumental digital health discourse was considerably lacking, since it failed to attend to some of the complex consequences of providing health care at a distance.

In sum, looking back over the early years of web studies reveals a degree of mythology about the Internet’s potential, whereby the few futurists and scholars who occupied this territory became

disproportionately influential at shaping the discourse about this subject area. The likes of Howard Rheingold [12] and even Sherry Turkle's [13] early work, were, on balance, minor influences in the trajectory of social scientific studies of digital health, but their libertarian claims are probably best ignored when attempting to engage with the development of the discipline's history. It is reasonable to be ambivalent about this state of affairs, since much of the instrumental research surrounding digital health - typified by the articles published in the *Journal of Medical Internet Research*—would benefit from greater scrutiny from a cultural theory lens. Indeed, a lot has changed since these early years of theorising the web and this deserves some critical reflection, so as to understand what interpretations are appropriate today to arrive at a more critical view.

## 2. The Mobile Web and App Culture

One clear insight from this early period is that it is important for researchers to consider what still needs to be investigated in digital health studies, but perhaps more crucially, what critical theoretical lens is most appropriate to address the complexity of what takes place online. We address this by focusing on the trend towards utilizing mobile devices to navigate the Internet. Mobile devices are playing an increasing role in the digital economy, experiencing more growth than computer sales worldwide. Furthermore, the number of mobile devices that exist in the world already exceeds the world's population. Moreover, it has become apparent recently that mobile web usage is in decline and, instead, a growth in mobile app usage has been registered [14]. This means that people are using mobile browsers and websites less, choosing instead to access content directly through mobile application stores, such as the Google Play store and Apple App Store. This is a compelling reason to study how people engage with their health via mobile devices.

Yet, it also appears that “mHealth” [5] is quickly becoming a core mechanism through which people become complicit in engendering systems of surveillance that can be framed by commercial or political interests. Unlike web browsers, which are relatively transparent in how they capture and monitor a user's data, users of mobile apps may have little understanding of how the data that is captured about their health is utilized. However, such data can have dramatic impacts on various industries who will happily pay for access to such information to further their goals, whether these are governmental or commercial. The increasingly ubiquitous presence of mobile devices ensures their place as a core driver of health engagement. The global significance of this cannot be underestimated, as mHealth is capable of functioning in environments where there is no cabled broadband infrastructure, which means it is more suited to use within nations that have limited infrastructures. The importance of the mobile device market and, in particular, 3G and 4G infrastructure is made apparent in the recent investments by both Google and Facebook in airborne Internet provision. Thus, studying mobile culture in the context of health is of particular value, as it resonates with the direction of travel in global communications in a way that more effectively alleviates the digital divide.

We also narrow our analytical lens even further by looking specifically at mobile health apps that relate to physical activity and lifestyle. Such apps, which allow users to track their exercise behaviour, body weight, and food consumption, represent a significant proportion of the health app market, making their communities a critical mass of interest. Indeed, exercise, body weight and

dieting apps are amongst the most popular downloaded health apps [15]. Moreover, 80% of the population in Europe has carried out a health-related search on the Internet [16] and mobile phone subscriptions worldwide reached nearly 7 billion in 2013 [17]. In this context, the present paper focuses on the utilization of self-tracking mobile technologies associated with physical activity lifestyle and health promotion.

Changes in public health promotion focused on “lifestyle” have been brought about by rapid developments in digital health technologies [18]. In recent years, healthcare and health promotion has operated through “e-scaped medicine” [19] no longer confined to clinical institutions but, instead, delivered through “diffuse and fragmented” networks of locations. This has led to a proliferation of research that explores how best to utilize digital systems to predict, diagnose, treat, and monitor health. At the same time, it has created patients who are much more inclined to use technology to monitor their health and, thus, be more complicit in their own surveillance, albeit within platforms where data that is consumed is under the watchful gaze of the platform owners and unspecified third parties who can purchase their data for their own goals. Indeed, one of the challenges with the growth of mobile health apps is the difficulty we have in understanding the information chain where our own agency becomes a commodity for use by other organizations.

In others words, while greater access to technology may have narrowed the digital divide, the rapid transformation of digital platforms—if only from Web 1.0 to Web 2.0 architecture—has widened the digital literacy divide. These circumstances compel researchers to think critically about the locations in which a public understanding of digital culture develops, beyond formal education systems. This is particularly important in the context of health, since being able to negotiate the digital terrain effectively can determine one’s capacity to experience greater autonomy or to derive greater insights into one’s health. Yet, one may look precisely to how education has also changed as a result of the Internet era and bringing together these two dimensions—health and education—is a helpful way of developing a critical approach to mHealth. Indeed, education has expanded beyond its conventional realms over the last decade. The trajectory towards lifelong learning, and even such programmes as “one laptop per child” or Sugata Mitra’s “hole in the wall” programme, speak to the wider spaces in which innovative educational practice is delivered through technology and often within a public context. Other examples, such as MOOCs and qualification “badges” each further articulate how traditional education systems are developing more publicly facing programmes.

### **3. A Public Pedagogy Approach to mHealth**

This shift has been accompanied by a groundswell of scholarship that draws on the theoretical construct of “*public pedagogy*”. Whilst the emergence of the field of public pedagogy has presented possibilities for new approaches to understanding education, it consists of varied perspectives. In their comprehensive mapping of the field and review of literature spanning 1894–2010, Sandlin O’Malley and Budrick [20] identify a lack of definitional theoretical clarity in the way in which public pedagogy has been conceptualised and applied across a broad set of literature, from the role of school in preparing young people for citizenship through to the public pedagogies of dominant

discourses. Approaches to public pedagogy have been informed by a broad range of literature including curriculum studies, adult learning, lifelong learning, critical pedagogy, feminist studies.

As an analytical device, public pedagogy is located at the intersection of numerous disciplines, including but not limited to pedagogy, sociology, and cultural studies. On this basis, it offers exciting potential for critical explorations of the relationships between the educative force of a range of cultural sites in people's lives and engagement with physical practices, corporeality and subjectivities. Inquiries into understanding how and what people are learning about the (in)active body through these emerging technologies aligns with a Physical Cultural Studies approach which David Andrews [21] (p. 45) defines as a:

“Synthesis of empirical, theoretical and methodological influences (drawn from, among other sources, the sociology and history of sport and physical activity, the sociology of the body, and cultural studies) that are focused on the critical analysis of active bodies and specifically the manner in which they become organized and represented, and experienced in relation to the operations of social power.”

A growing body of influential work has examined the impact of new media on the organisation, representation and experiences of the body, operating within these various physical cultures Andrews describes above. Yet, as Freishtat and Sandlin [22] observe, there has been a limited body of work exploring the *public pedagogies* of technologically mediated spaces. This reveals a lack of explicit focus on the pedagogical processes operating in the digital environments described above. Drawing on a range of theoretical perspectives, questions have emerged as to how far health professions and individual users of technologies are prepared to incorporate these kinds of technological applications into their lives and what kinds of ethical issues might arise. Their legitimacy and desirability has been the focus of a number of important contributions to this debate across a range of disciplines (philosophy, surveillance studies, social sciences, cyberstudies, new media studies). The relationships between these technologies and their users have been explored through various theoretical perspectives of surveillance and governance, but these have not framed the relationship as one of learning or pedagogy. In attempting to contribute to this developing theoretical discussion, we approach these issues from a different perspective, endeavouring to make clear a justification for a critical engagement with mobile health technologies from a public pedagogy approach. Thus, we wish to reposition a critical perspective on digital health and suggest that an effective way of doing so is through the lens of public pedagogy. We do not argue that this approach should replace others, but that it offers a complementary approach within a multidisciplinary critical perspective that is capable of synthesising a range of critical priorities in how we analyse digital health interactions. As Hickey-Moody and colleagues [23] argue, public pedagogy approaches function as “bridges or rather, as multiple crossing points, between the fields of education, sociology and cultural studies”.

Each of these transformations to understanding education and mHealth speak to a wider opening up of what were previously closed practices—health and education. What took place in each of these areas of society was locked behind institutional systems, such as schools, universities, doctor's surgeries and hospitals. In the era of mobile health, these encounters with health and

education have become more public facing, social experiences. Furthermore, there is a trend towards greater visibility in digital spaces, a theme made evident in the recent popularity of “selfies”—self portrait photos taken on mobile devices. Indeed, a helpful example in the crossover between health issues and digital visibility is the recent “dare to bare” campaign, which saw women sharing selfies online without wearing makeup in order to show solidarity and support for cancer sufferers. Various commentaries have emerged around this grass roots phenomenon, but what seems salient to our inquiry is the way in which self-mediation interfaces with health and the manner in which somebody’s public self is a vehicle for health communication and education. Thus, creating a #daretobare selfie photograph may be considered a political act, as it engages people with discussions about authenticity, identity, solidarity, health and selfhood, while also forces us to think about representation and individuality set against a proliferation of celebritised, photoshopped images which bear little resemblance to real people. Individuals who chose to ‘dare to bare’ were exercising their empowered, socially situated selves and, in so doing, were actively raising awareness about the need for cancer research, if not as individuals, then as a collective.

Explaining the trend towards greater visibility in digital space requires a range of conceptual apparatus, but Ruckenstein [24] (p. 68) gets close to what is at stake when discussing how “smart phones and tracking devices” have created a “field of personal analytics” and “self-monitoring practices”. Thus, we steer away here from concluding that either digital technology is taking us towards a utopia where its users feel necessarily empowered or better off, or that digital media will ultimately enslave us to some dystopian nightmare scenario. Rather, it is useful to contextualise this distinction between perspectives that celebrate the value of digital technology and those that adopt a more worrisome approach. The rise of mobile health apps does not simply respond to a vision of health, but can also be considered characteristic of a “confessional society” [25]. To this end, we ask what theoretical frameworks might aid us in yielding more complex and nuanced understandings of surveillance within these contexts and help mediate between the above dichotomy. By drawing from, and building on, the contributions of an emerging field of public pedagogy scholarship, it is possible to ask different, perhaps deeper, questions about individuals’ engagement with digital health technologies.

In advancing a public pedagogy approach to theorising digital health, it is necessary to recognise how technology is inextricable from the manner in which people learn about health. Furthermore, these apparatus dictate conditions of self-tracking, collection of data, and monitoring, which have a bearing on what and how people learn about their bodies and health. Yet, there is no singular approach to public pedagogy and so it is crucial to first clarify the analytical approaches they offer in critiquing digital health. Thus, we draw from the work of Jake Burdick and colleagues in “problematizing public pedagogy” [26] and we examine the utility of its current application and appropriation, while endeavouring to build on and develop this body of work so that it develops a more critical perspective of digital health.

Public pedagogy scholarship is flourishing at a time when the distinction between public and private spaces has been significantly complicated and confronted by our emerging digitality. These conditions frustrate some of the established narratives around public pedagogy scholarship. Thus, we are cautious to claim that these pedagogical forces lead to transference, or simple forms of

governance. Instead, we seek to understand: “how these educational sites and practices actually work to teach the public and how the intended educational meanings of public pedagogies are internalised, reconfigured and mobilized by public citizens” [20].

Given the diversity of approaches to public pedagogy, what should be meant when invoking this concept to make a case for a more critical perspective of digital health? Whilst public pedagogy is a contested term, there is some general consensus within the field that it comprises a focus on the kind of learning that takes place *outside* of formal schooling. Thus, in developing an account of digital health as pedagogical, it is necessary to start with a vision of education that recognises how learning—albeit about one’s body and health in this case—can occur in sites and contexts beyond formal schooling. This is precisely the approach that has characterised public pedagogy in recent years. A number of notable theorists [27–32] have drawn attention to contemporary sites of learning beyond the boundaries of formalized education sites, forming what has been announced as the field of “public pedagogy”. Attention has therefore been recast in educational research towards processes of education that take place across a variety of sites, including museums, zoos, libraries, media, popular culture, commercial spaces, grassroots activists movements, and more recently through the work of “public intellectuals” (see [20,32]). In this paper, we extend this also to digital platforms, such as social media environments, which are being positioned as technologically mediated pedagogical spaces [22]. Yet, as Freishtat and Sandlin [22] (p. 505) go on to suggest “there is a significant gap in the literature inquiring into the emergence of technologically mediated spaces as locations of cultural production, education, and learning among youth.” Furthermore, in line with the critiques by Glen Savage [33], the multiplicity of public pedagogy approaches raises questions about what counts as “pedagogical” phenomena. In digital health environments, this may be especially difficult to discern, since many of them may not be recognisable as “learning” environments.

Nevertheless, it is reasonable to acknowledge that a necessary, if not sufficient, condition of public pedagogy’s utility lies in its focus on understanding education, as it occurs in sites beyond formal institutions. Underpinned by theoretical contributions from cultural studies, feminism, pedagogy, and other disciplinary perspectives, the focus of public pedagogy has been on more resistant forms of critical pedagogy, and on identifying dominant discourses, drawing attention to the educational force of popular culture [34]. However, recognising public pedagogy as a distinct field remains somewhat premature, as its conceptual trajectory is still being formed. Hickey *et al.* [23] propose the term “pedagogy writ large” to capture a general set of theoretical conceptualizations “public pedagogy” and “cultural pedagogy”, which frame pedagogy in this broader sense.

Therefore, a perspective of digital health arising out of public pedagogy approaches must be mindful of the tendency for scholars to cite the “term without adequately explicating its meaning, context or location within differing articulations of the construct.” [26] (p. 3). In doing so, whilst we advocate the need for an educational framing of digital health, we also consider the work of Burdick, Sandlin and O’Malley [26] and Savage [33] to be essential, when extending and problematizing notions of public pedagogy in the context of mHealth. At such a juncture, Budick *et al.* [26] (p. 3) offer an instructive trajectory for public pedagogy, based on an architecture of three key areas; “*framing*, exploring the problematics of public pedagogy’s definition, the organization and historicity; *studying*, emphasizing the ways in which our research simultaneously



illuminates and obfuscates the object of inquiry; and *enacting*, taking up the ways in which we view and engage with our own pedagogical acts outside of institutional spaces.” This provides a useful architecture through which to outline a public pedagogy approach to digital health, whilst also calling into question some of the tensions inherent within these approaches. By drawing on their framework, we simultaneously apply public pedagogy to our critique of mHealth, while also exploring the problematics of its current definition (framing), and considering how this obfuscates certain aspects of learning through technology (studying).

#### 4. Governmentality and the Public Pedagogies of “Nag Technologies”

If public pedagogy is characterised by how learning takes place outside of formal educational structures, then clearly a prominent feature of where such learning takes place is within those informational spaces that surround every day life, notably digital spaces. To this end, a further characteristic of public pedagogy may be the conditions of such experience, which, we recognise, has to do with the way people negotiate their public persona and the manner in which they are complicit in self-surveillance. After all, the promotion of healthy behaviours through mobile apps has intensified processes of surveillance and regulation of people’s everyday lives, raising a number of questions about their applications. Such devices as iPads, Fitbit wristbands, patches, or GPS equipment, require users to collect and log data, which builds a profile of their lifestyle, including where they have walked, how fast they walked, and what they did along the way. Indeed, part of the appeal of these tools is that they *gamify* [35] the experience of monitoring health, introducing playful dimensions that encourage user participation. This may include documenting exercise habits, diet, weight with reward systems, motivational tools, and all of this data builds a sense of the “quantified self” [5,36], while also linking this publicly through social media. Products such as the Nike+ fuelband (a wristband designed to monitor and measure “whole body movement”) is a good example of this, since it also has a built in capacity to share achievements with friends. Thus, the platform integrates a public dimension predicated on the user’s interest to share what they have done.

Users of these technologies are complicit in shaping the culture of self-surveillance that underpins digital societies and the degree to which people share what they do may speak to a willingness to be subject to an outsider’s gaze upon their bodies. Yet, the legitimacy and desirability of these technologies has recently occupied public attention, with recent news media documenting the rise of what has been termed “nag technology”—that is, technology which persistently nags its user to be active and live a healthy lifestyle. The cultural and regulative connotations of this term are clear to see. The public pedagogic focus here is on the “dominant cultural discourses” within “popular culture and everyday life” [20], which compel people towards healthy behaviours. In other words, users are asked to learn how to look after themselves via the disciplining regularity of the device’s presence and regular notifications to maintain their good behaviour. According to Sandlin *et al.* [20], current approaches within public pedagogy draw upon popular pedagogies to, “to link cultural and media artifacts to processes of social domination”. Perhaps the most well-known theorist to have contributed to this work is Henry Giroux [27,37]. Giroux’s work on popular culture and pedagogy and, particularly, “corporate public pedagogy” as a

“a powerful ensemble of ideological and institutional forces whose aim is to produce competitive, self-interested individuals vying for their own material and ideological gain” [38] is particularly informative here. Furthermore, Giroux has been crucial in fashioning contemporary understandings of the educational force of such popular cultural sites as film, television, and the Internet.

Public pedagogy work of this nature draws on principles consistent with a focus on the dominant discourses promoted through educational sites, and the ways in which popular culture is utilised as a form of governmentality. From this perspective, dominant discourses of digital health are inextricably tied to the neoliberal discourses flowing through these digital technologies, demanding the neoliberal subject capable of acquiring information, monitoring and adjusting their bodies/lifestyles in relation to this information. Imbued with the negative implications of these technologies, which are partly consistent with the dystopian perspectives on digitality described earlier, it calls into question the narratives of empowerment that advocates of digital health would have us believe are the outcomes of a digital life.

When endeavouring to make sense of these shifts, Lupton [5] observes that the rapid growth and popularity of “mHealth” reflects the trend towards self-tracking as a way of managing one’s lifestyle in line with the logic of a growing movement known as “the quantified self”, where one collects and charts data, shares it and gathers real time feedback about it, which is then used to take better “care of the self” [39] and modify one’s behaviour. This may involve sharing how far one has run and receiving encouragement from friends, which then incentivises the user to continue, or making weight loss targets. From this interpretation, one can critically explore how these digital devices act as pedagogical devices through certain pedagogical frames, such as the quantification of self, the confessional, surveillance, and the importance of self-evaluation. Mobile health technologies, particularly those associated with health promotion, exhibit particular pedagogic processes in the management of bodies. The transparency of these lessons provides a critical framework through which to examine the regulative force alluded to in this populist terming of digital health. Thus, mobile apps and social media sites are some of many examples of media texts or artifacts that warrant analysis as vehicles of *public pedagogy*.

With their accompanying processes of surveillance and evaluation, these technologies imply expectations of control, which are to be learned and reproduced by users. In this fashion, the appeal and explanatory potential of this conceptualisation lies in its analytical focus on the connection between popular culture and neoliberalism in explicating its educative force in the management of bodies through new digital health platforms. Pedagogically, this represents a shift from learning digital norms of techniques of the body [40]—of users knowledge of “how to use their bodies”—towards a focus on learning how to use information “about their bodies” [40] (p. 70). A good example of this is a mobile app that required users to make necessary plastic surgical interventions to an avatar to make her beautiful. As one tech magazine writes: “The game...rated for children 9 and older...walked players through the graphic steps of liposuction that must be performed on an “unfortunate girl” to make her “slim and beautiful” [41]. Compelled by a Twitter protest campaign going under the hashtag #EverydaySexism, the app was eventually removed from the App store.

Such an example raises questions about how, increasingly, younger people engage with these technologies as pedagogical devices through which they learn to recognise themselves and/or others as good, healthy, active and/or having desirable bodies in the pursuit of “healthiness”. Framed through the lens of public pedagogy, young people use these participatory technologies to learn not only about “health” activities, but also of what and whose bodies may be valued, given status, and how to meet the expectations of particular body pedagogies [42]. In the plastic surgery app, fatness is depicted as “matter out of place” [43] to be removed through processes of extreme modification. The regulation of and management of bodies in these mobile apps and social media environments corresponds with an idealised version of acceptable bodies and the abjection of others’ bodies. In adhering to the corporeal order and normalisation of thinness, users are exposed to particular body pedagogies. Moreover, these applications depict particular bodies and subjects as marginal, different or even problematic and abject. Through game playing scenarios, the removal of adiposity through surgery reinforces the idea that “if embodied subjects fail to conform or perform to bodily norms, they stand to be classified as expendable waste; a waste that must be purified or hidden if society is to be maintained as a realm of order and productivity.” [44] (p. 3). In the plastic surgery app, bodies that are overweight are therefore positioned negatively as abnormal and in need of modification, in contrast with the embodied subjects that emerge after surgery.

The educational function of these apps is to normalise the fight against fatness or obesity, which, in turn, may influence and condition its users. Therefore, these digital spaces emerge as important pedagogical devices, as they become sites through which users learn about their own and others bodies and “add to an understanding of how a curriculum of enculturation occurs within the social context of networked technologies” [22] (p. 509). Similarly, in the context of health promotion apps that monitor and regulate body data, Lupton focuses on “the kinds of meanings and the representation of the ideal subject that are related to the use of these technologies in the interests of promoting health” [5] (p. 232).

While it is apparent that one should question the legitimacy of the learning that takes place here, a deeper, more critical reading of the phenomenon relates to the pursuit of *sharing* the experience. Thus, what distinguishes public pedagogy in a digital environment is that the learning does not simply end with the user’s experience, but that these “lessons” are then pushed out to wider communities. The consequences of such sharing also require exploration. Beer and Burrows [45] argue that “web cultures are defined by the consumption of the mundane”, particularly through social media sites where a range of personal information about the user’s everyday life is often made readily available. Whilst the criticisms of this may vary, it may be useful to focus on the explanatory potential of the “confessional society” [25] that such sharing describes, whereby there is an accompanying obligation to live private lives publicly.

These conditions are inextricable from the rise of the Web 2.0 ethos and the structural principles that govern these practices. Through a “culture of connectivity” [46], personal lives are organized around the retrieval and public display of data about a diverse range of aspects of one’s body and lifestyle. In the process of collecting, visualising, sharing and monitoring such data on one’s body in a public space, users learn about the body in terms of appropriate forms of maintenance, development and repair [47]. The blurring of health and these inter-personal communications

involves a process of self-presentation online, which is achieved by sharing images and text. Yet, the public sharing of information and images about one's body and health, raises questions about new, potential vulnerabilities, such as online bullying, which has been identified as a particularly significant risk to children using the Internet in Europe [48]. It is thus particularly important, to consider the interface between learning via public pedagogy and more formal educational learning, perhaps making social media education as crucial as religious, drugs, sex, financial or pastoral education within a national curriculum.

So, the critical approach to public pedagogy espoused here, focused on interrogating broad dominant discourses, helps us to identify the neoliberal educational forces associated with consumerism, where commercial platforms introduce “new modes of surveillance” [46]. Certainly, this work provides central tenets for us to scrutinize technology from a critical perspective, assisting us in formulating an understanding of the political, social and cultural norms that shape citizenship through public pedagogy encounters. This is particularly important in the case of commercial health apps, which contribute to powerful discourses of the body in the context of consumerism that saturates most online environments [22] (p. 507). However, such interpretations of mHealth might be indicative of what Savage [33] terms the “enveloping negativity”, which has plagued public pedagogy.

## 5. Relationalities of Digital Health Pedagogies

Thus far, we have recognised how public pedagogies of digital health must be located within perspectives that Sandlin *et al.* [20] define as propagating “dominant discourses” and reinforcing the “popular culture and everyday life”. From this understanding, we have highlighted the tendency to polarise perspectives that may lead us to characterise digital health as wholly serving a surveillance society, when it does not. Rather, surveillance takes on a new meaning in a digital age, given the range of complicity that it implies by sharing one's “quantified self”. Nevertheless, such perspectives offer important contributions to, for example, examining “the implicit curriculum of technologically mediated spaces and their public pedagogy” [22] (p. 507). Thus, despite the absence of explicit learning goals within such informal spaces, they nevertheless foster certain kinds of learning.

Whilst Giroux's work has been influential in recent applications of scholarship claiming to focus on public pedagogy, we must be cautious of appropriating such ideas in a vein that diminishes our capacity to understand the complexities of “cultures of connectivity” [46]. In this vein, we posit that, alongside the focus on the “content” and curriculum of digital health pedagogies, one must also consider the *pedagogical relations* that frame people's experiences of health within digital spaces. Thus, we now turn our attention to the “relational aspects of inhabiting a place and how these shape subjective experience with the kind of relational encounter that may occur” [49] (p. 57).

Our interpretation of public pedagogy as occurring within informal, digital, social spaces, captures the pedagogical features of technologically mediated health sites, whose form may be adequately encapsulated within the term “biopedagogy” [50]. Through this lens, we are able to make visible the discursive and educational forces, which evoke self-management techniques and neoliberal practices of the self. However, a focus *only* on the meanings found within the sites of

digital health, and accompanying neoliberal modes of regulation, would be antithetical to our aspirations to better understand the complex pedagogical processes of these apps from a critical perspective. This may also leave a number of critical and complex questions unanswered, such as developing an understanding of the supportive role played by the network within these spaces, irrespective of what is learned formally about health. Perspectives characterised by visions of techno-dystopia, therefore, may be troubling in the sense that there is a danger of latent assumptions of docility present within their readings of technology. As Walkerdine [51] (p. 201) suggests “a relation between the effectivity of biopower and the subject working on the self, or resisting, is too simplistic...health works in complex ways to produce subjectivity and that we cannot just read subjectivity off from biopolitical modes of regulation”. To do so, would be to invoke a techno-dystopian reading of these modes of regulation.

Whilst users might all experience the discursive organisation of their bodies through health apps, the public pedagogies we explore here may help us to understand how users experience this in relation to different “regimes of meaning” [52] which are *formed relationally*. In this sense, we may extend these pedagogical notions to consider the different relations of affect circulating through the intersecting publics that emerge online. In other words, whilst digital health technologies are the site of regulative discourses and practices, the adoption of these practices is not simple, nor can it be assumed in the broader readings of public pedagogy. As Ruckenstein observes, “the ways in which people confront and engage with visualized personal data are as significant as the technology itself” [24] (p. 69). But more than this, the way people experience discursive relations within these technologies is in relation to the circulation of affect through corporeal and prostheticised bodies. At the same time, there are critiques that broad visions of public pedagogy have been plagued by an “enveloping negativity” [33] through the focus on social dominance. Against this background, the call by Burdick *et al.* [26] to consider what our public pedagogy approach “obfuscates and illuminates” is even more salient in the context of understanding embodied learning through digital health. In other words, a focus on the biopolitical may help to define, but also limit, the reach of conceptualisations of embodied learning and the complexities of the body in digital spaces.

It is not that a focus on dominant discourses fails to provide valuable insight, but rather it we need be caution of focusing only the *content* of pedagogy rather than its *relational* derivation. Savage [33] warns against such “totalizing and mythologizing” approaches to public pedagogy, which become all encompassing and through which “popular public pedagogies, therefore, are reduced to little more than mechanisms for exercising ideological domination” [53] (p. 85). Our understanding of connectedness of bodies with technologies and other bodies is diminished as a result of this narrow approach and the potential for understanding the complexities of resistance, negotiation and contradiction may be obfuscated. In this sense, our critique extends the conceptual apparatus we bring to public pedagogy to make sense of what happens in mHealth experiences.

To recap, our approach to understanding mHealth rephrases the question of pedagogy in the context of *relationalities*. We argue that, rather than focusing only on the politics of digital health, or on the meanings it produces, we must consider the “complex, moving webs of interrelationalities” [30]. The importance of this relational approach is further evidenced by the

reliance within public pedagogy on an increasingly unsustainable distinction between public and private [53], which is blurred by digitality. Whilst the commercial intrusion of media has been recognised elsewhere, web 2.0 technologies further compromise what may be understood as “private” matters. This presents a number of risks that are broader than those which are typically associated with life online and to the (re)framing of pedagogical address, as often occurring in unpredictable ways. Understanding how people learn to recognize themselves and/or others ‘as good, health, active desirable bodies in the pursuit of “healthiness” within these environments means avoiding a simple distinction between “virtual” bodies and “offline worlds” or between public and private spaces.

As Glen Savage observes, this recognition reveals the complexities that arise from *intersecting publics*, when conceptualising of public pedagogies of the body [53]. Thus, our task in developing a critical perspective on mHealth is to understand and identify the extent to which pedagogical forces extend and “link people together as a *public*” [53] (p. 80) or as a learning community. Freishtat and Sandlin [22] (p. 505) suggest that social media can be understood as producing a *habitus*, such that a users “experiences with technological culture influence the ways in which they will interact with technology”. Moreover, an individual’s engagement with their body occurs dialogically in relation to family, gender and socio-cultural and local contexts, as they engage with these digital spaces. So, on the one hand, these apps and their accompanying imagery of the desirable body, engage people with particular body pedagogies, though they are also re-imagined through local meanings and contexts. This reading of digitality frustrates conceptions of technology that might position it as ultimately surveillant and disempowering in an absolute sense, rendering people devoid of critical agency. After all, such perspectives behave us to ask how complex relationalities are created in these digital environments and how they work across complex and intersecting ways. In other words, the analytical focus is not simply on the meanings which are transmitted through body pedagogies. Nor is this to focus attention on those engagements with the digital that are simply about resistance. Rather, it means focusing on the relationality between technology, its production and reception as a pedagogical process. The spaces within which this interaction occurs may mean that surveillance and ideological oppression are stronger. As such, even where there are evidenced moments of resistance, these may not be as strong as the powerful forces of surveillance of body pedagogies that may be oppressive, normative or damaging.

## **6. Public Pedagogy for Disembodied Cyborgs**

Many approaches to analysing digital health encounters presume a relatively fixed notion of selfhood, the body, and corporeality. Yet, we are at a unique moment in human history where the body is made more complicated by its posthuman technological mediation and prostheticisation. These circumstances are made apparent in the trajectory towards mobile culture, where the mundane cyborg is made manifest in the way that mobile devices become extensions of ourselves and our bodies. Their transformation into wearable technologies like Google Glass and the Oculus Rift, reveal how biopedagogies are mutating around the hybrid body.

To this end, a final dimension of the public pedagogy approach to digital health requires us to consider the embodied nature of pedagogy and how that is changing. As Gaztambide-Fernandez

and Arraiz-Matute [49] (p. 57) argue, conceptualising technologies as pedagogical means taking “account of the desires, intentions and conditions that produce them as such”. In this vein, understanding how and what people learn about their health in technologically mediated environments means recognising the importance of embodiment in articulations of learning within theories of public pedagogy:

Public pedagogy articulates this embodied process through which subjectivity is produced and the politics of this process need to be considered across a broader array of spaces, texts and through new theoretical assemblages. Embodiment, therefore, cannot be overlooked in any consideration of the consumption of popular cultural forms [23].

An attempt to define a more embodied and affective understanding of learning is found in Probyn’s [54] exploration of materiality affects in the classroom and her focus on “what actual bodies in the classroom do”. In turn, this has given rise to discussions about relationalities between bodies as an important aspect of pedagogy, but which have yet to be applied to the context of embodied learning in digital environments. Our intention is not to advance theoretical approaches occupying the “turn to affect” (see [55,56]). Rather, it is to recognize the importance of applying an embodied approach to public pedagogies of technologies *alongside* the important, but broader, political focus of the dominant discourses of neoliberal regimes of health, the body and citizenship. Approaching digital health in terms of both its biopolitical and embodied nature enables us to engage with critical approaches beyond those operating a broader “levels of abstraction” [54] (p. 25).

Inspired by Deleuzian frameworks, such work focuses on the body in terms of capacities and transformations [57,58] as it is brought into connection with other bodies and technologies [57]. Such conceptualisations are significant insofar as they require us to consider broader ontological complexities and debates about the virtual body, where the body is considered to be both absent and present. The disruption to our bodily continuity that follows from life within mobile digital worlds, requires us to revisit longstanding philosophical and sociological assumptions about what a “body can do” [54,59,60]. Thus, attending to the relational aspects of “inhabiting (digital health) spaces” [49], also means understanding the embodied history that is brought to bear on the affective response one has to new engagements with the body emerging through wearable technologies, visualisation of data *etc.*:

What constitutes an affective response is hugely complex, and is in part the result of an embodied history to which and with which the body reacts, including how the classroom is conceived and practiced [54] (p. 30).

New sensorial experiences, such as the wearing of fitbit health bands, which vibrate when you achieve your activity goals, combine different pedagogical forces to produce embodied ways of knowing. These new knowledges are not just about techniques of the body [40] (p. 70) or users knowing “how to use their bodies” but also reveal how to use information *about* their bodies in accordance with the affective responses to that information. In this sense, we can conceptualise digital health as existing at the nexus between discourse, affect and pedagogy and through which subjectivities are constituted as a relationality.

In sum, critical analyses of digital health should engage with “considerations of the affective nature of public, popular and cultural pedagogies” [23] (p. 234). This means a sharper analytic focus on the emotional exchanges occurring in the social media spaces associated with these health apps and the affects emerging through interactions between embodied persons, including those that are constituted as “digital bodies”. The inter-corporeality and “trans-subjectivity” [56] of bodies, means we cannot think of their presence in digital spaces as singular and bounded. They are connected to other bodies through digital platforms and with technologies; increasingly so as we move towards web 3.0 and the Internet of Things. Thus, the prostheticised body occupies spaces of ambiguity where it is always unfinished and always compelled to improve its digital rendering.

The affective flows of pedagogy in these digital spaces can operate as both power and pleasure. The Web 2.0 era marks a shift towards health platforms that are oriented around what might be described as “playful” environments. The mashing up of the quantification of self through the collection of data about oneself, with creative and game play scenarios, is a recent trend described by Whitson [35] as “gamification”. This is notable for the way in which “playful frames” are “applied to non-play spaces” [35] (p. 166). In this way, digital health pedagogies may be experienced as “play” [35,61,62]. Many contemporary health and fitness apps draw on gamification whereby “playful frames” are “applied to non-play spaces” such that everyday tasks, such as running, become more enjoyable or more like a game. *Zombie Run* is a prominent example of this trend; an app which combines social media technology with game play situations featuring zombies, as stated on its website “Join 800,000+ runners on an epic adventure that motivates you to run further and faster than ever before—whether you’re a beginner or an expert!”. To this extent, such explanatory concepts reveal how applications engaging with gamification can neither be reduced to being simply oppressive, nor emancipatory. On the one hand, *Zombie Run* exhorts individuals to undertake physical activity and monitor and regulate one’s lifestyle. At the same time, users might experience more pleasurable aspects of physical activity, such as exploration of local space through new running routes via the zombie play feature or new routes suggested by running apps. For a participant of these environments, it may be possible to experience both, at the same time. Other examples include health apps that use rewards for healthy eating habits. So, through pedagogical processes like gamification, digital health technologies are normative, regulatory and resistant. Digital health may therefore present new frames of engagement which can be both enabling and constraining at the same time. In this sense, digital environments present us with perhaps, multiple and often contradictory pedagogical forces.

These examples situate health apps in the complex body-machine assemblages through which bodies enter into complex inter-corporeal affectivity, experiencing pleasure, shame, disgust, enjoyment. Probyn [54] (p. 26) describes how “affect amplification makes us care about things”. Many health apps monitor users movements and bodily functions and require users to upload data wirelessly. Many users have the opportunity to share their data in social media environments, sharing data or discussing behaviours with others online. The linking of bodies in these spaces is indicative of bodies entering into entangled processes, and the affective capacities, even where the corporeal body might not be present. In this sense, rather than simply being shaped by social influences, bodies entering into these digital assemblages are part of the co-constitutive process.



These inter-subjective encounters are a crucial component of public pedagogy, where “subjects come into relationship and influence each other” [31,49]. Perhaps crucially, one of the questions that arises from this is “whose desires and intentions are enacted and imposed pedagogically and to what end...who is it we want people to become” [49] (p. 59).

## 7. Conclusions

This paper has outlined a critical approach to understanding digital health in the context of theories of public pedagogy. It began by arguing on behalf of a public pedagogy approach, before setting out some of the formal parameters of this that are most suited to an analysis of digital health encounters. In so doing, we have outlined differences within public pedagogy theory and highlighted how “theories of “pedagogy writ large” have the potential to provide diverse traditions with a mediating concept between the production of knowledge or ideology and the normative power it exercises” [23] (p. 234). We went on to outline how public pedagogy approaches draw attention to the neoliberal governance of the body, which occurs through digital health encounters. However, we also acknowledge the limitation of this broad vision of public pedagogy, which can obfuscate the various ways in which multiple pedagogic forces intersect, which is particularly prominent within virtual worlds. As such, we present a conceptual framework for public pedagogy that takes into account the limitations of a focus on digitality as popular culture at the broadest level. This approach emphasises more complex processes that operate around crucial categorical distinctions, such as between the virtual and non-virtual, the individual and the community, public and private, and formal or informal educational structures. We have also acknowledge the changing conditions of embodiment that arise from a trajectory towards greater digitalization, where “online bodies are bodies that are certainly being written, but simultaneously bodies to write on” [63] (p. 229). In the digital apps we describe, users are not merely the “machine parts” [63] (p. 219) of the human–computer interface, but are made “more autonomous” [63] through their “symbiotic relationship to machines” [63].

There is a lack of research on individual’s experiences of these technologies, particularly in terms of the implications for “embodiment, selfhood and social relationships” [5] (p. 299). The intention here has been to recognize the importance of applying an embodied nature of pedagogy alongside broader political focus of public pedagogy [34] to better understand how digital health encounters take place. Making the body more central to conceptualizations of public pedagogies of technology, while attending to the political and affective dimensions of technological relationships, ensures a more critical understanding of what occurs in digital health, since it does not neglect how the relational dimensions of networked experiences brings an additional pedagogic layer, beyond the content. This approach provides a useful way of negotiating the polarisations between utopian and dystopian views of digital health, but it does not ignore or diminish the aspirations or anxieties that arise from these views.

## Acknowledgments

The authors would like to acknowledge the support of the University of Bath and the University of the West of Scotland.

## Author Contributions

This article was co-devised and co-authored by Emma Rich and Andy Miah. All authors read and approved the final manuscript.

## Conflicts of Interest

The authors declare no conflict of interest.

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# Practicing Patienthood Online: Social Media, Chronic Illness, and Lay Expertise

Collette Sosnowy

**Abstract:** The use of digital technologies and social media by people with serious illness to find, share, and create health information is much celebrated but rarely critiqued. Proponents laud “Health 2.0” as transforming health care practice and empowering patients. Critics, however, argue that a discourse of developing lay expertise online masks the disciplinary practices of the neoliberal state’s emphasis on individual responsibility. Notably, the perspectives of people who are engaging with social media related to their health and illness are under-represented in this debate. This research examines the experiences and perspectives of women who blog about their lives with Multiple Sclerosis in order to situate them in the context of these conflicting ideologies. Methods consisted of an ethnographic content analysis ( $N = 40$ ), an online survey ( $n = 20$ ), and an online discussion forum ( $n = 9$ ). Findings revealed that blogging is neither inherently empowering nor inevitably disciplinary. Rather, it simultaneously offers opportunities for patients to gain medical knowledge and resist medical patriarchy, as well as compounds expectations placed upon patients to assume greater responsibility for managing their care.

Reprinted from *Societies*. Cite as: Sosnowy, C. Practicing Patienthood Online: Social Media, Chronic Illness, and Lay Expertise. *Societies* **2014**, 4, 3166329.

## 1. Introduction

Social media platforms facilitate the sharing of health information between users and the co-creation of new knowledge that is shaped by personal experience. As such, they are a unique location to read narratives of women’s experiences with illness because they provide insight into lived experience as told through a public forum. Social media can provide important spaces for people with illness to build community, engage in activism, and enact resistance. Numerous studies document the perceived benefits of using social media and being part of online illness communities [1–11], opportunities for people to find information and develop medical knowledge [12–17], and challenge medical expertise [18]. Ziebland and Wyke [19] identified multiple domains through which online activity can affect health, several of which fulfill social needs, such as connecting to others and narrating experience. They argue that the appeal of hearing about others’ first hand experiences as well as the ability to contribute to and construct medical knowledge are important components of seeking health information online. Certainly, social media applications are a key facilitator for these activities.

Skepticism of the internet as a reliable source of health information and resistance from some health care providers have lessened considerably since early widespread adoption of the medium [19]. Applications like blogging are now helping to facilitate a shift in patients’ roles [15,17,20–26] in which they are increasingly both enabled and expected to develop lay expertise about their illness and treatment, including seeking and sharing health information online through interactive

networks. Equally, practitioners are supposed to encourage these activities and welcome patients as partners in care [27]. People with illness who use social media are often portrayed as technologically-empowered citizens who actively strive to participate in their care, collaborate with providers, educate themselves and others about their illness, and self-manage their care.

While laypeople have initiated many of these social media practices, the health care industry has further promoted them as part of a model of participatory patient-hood that has the potential to “revolutionize” health care by accelerating knowledge development and contributing to advances in research, ultimately improving treatments and outcomes. Many companies, organizations, and agencies in the public and private sectors of the health care industry have rushed to position themselves in the social media landscape in order to market, shape, and influence their sectors of the economy as well as influence policy. They use the internet to promote a discourse that participation in social media is inherently empowering and that patient engagement via this media will dramatically shift health care for the collective benefit. Examples can be found on the websites of health insurance companies, advocacy organizations, and other industry stakeholders that feature patients who blog or appear in video presentations talking about their personal experiences with illness and treatment. While these profiles highlight the significant experiential knowledge patients have acquired and developed on their own, they also imply that taking on this role is inherently empowering rather than a product of necessary labor.

Critics, on the other hand, argue that this vision of participatory patient-hood, which incorporates a discourse of individual responsibility that is characteristic of neoliberalism, masks disciplinary practices of the state. As Foucault [28] conceived, discipline of the citizen is achieved in part through the indirect means of guiding individuals to discipline themselves. Drawing from Foucault’s technologies of the self, Rose [29] argues that under neoliberalism, a political, social, and cultural ideal of an “enterprising self” who strives toward an idealized conception of the citizen reproduces the reductive effects of neoliberalism. More specifically, this conception has come to include using internet applications to acquire and share information in order to direct, manage, and improve one’s health. In framing these practices as acts of choice, the shifting of responsibility from the collective to the individual is simultaneously celebrated and downplayed.

While neoliberalism is fundamentally opposed to collectivism, the potentials of social media to collect massive amounts of data and influence large numbers of people provide another venue through which to discipline and profit from citizens. Individuals are encouraged to donate personal health information and labor in the name of furthering medical innovation, thus benefitting the greater population. Meanwhile, both the health care industry and the state profit directly and indirectly from their efforts. A discourse of health activism reorganizes collectivism and turns it around so that it is no longer an oppositional practice, but a cooperation between public, proprietary, and personal interests. The promotion of using social media to conduct and maintain self-disciplinary practices can also be seen as reproducing structural inequalities by deflecting attention away from the inadequacies of the state and industry to care equally for its citizens and by excluding people who cannot or choose not to practice participatory patient-hood.

Lost between the divergent viewpoints of industry advocates and academic critics, however, are the voices of people who are engaging with social media related to their health and illness. They

blur the boundaries between these ideological distinctions through their lived experience with illness. In practice, patients must negotiate between these perceived opportunities and obligations to meet their needs. This research focuses on the social media of blogs as narratives about life with chronic illness, in order to understand how blogging is a forum through which these negotiations are related and practiced.

## **2. Situating Social Media in Health Discourse**

Miller and Pole credit the user-generated content characteristic of a more interactive online environment with being responsible for the rapid growth in health-related content online and call blogging the “quintessential Web 2.0 application” [12] (p. 1514). Digital technologies and social media have become so integrated in shaping a new cultural paradigm of health care that some in the industry have coined the term “Health 2.0”, which Sarasohn-Kahn defines as “the use of social software and its ability to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health” [22] (p. 2). Eytan best describes the concept’s ideological goals and discourse:

Health 2.0 is participatory healthcare. Enabled by information, software, and community that we collect or create, we the patients can be effective partners in our own healthcare, and we the people can participate in reshaping the health care system [30].

Such impassioned and enthusiastic discourse found in the quote above is common among advocates of this approach, illustrated here by such terms as “partners”, “reshaping”, and even “we the people”.

The ideologies behind Health 2.0 need further examination. Writing about personal data-reporting online, Levina [31] argues that donating information via online social networks creates the perception that “active patient citizens” align themselves with acts of rebellion against the traditional medical patriarchy that seeks to maintain control of health information and expertise. However, this idea can obfuscate problematic aspects, particularly the ethical implications of who else benefits from this freely-given data, that is, the companies that sell it. Rose and Novas argue that the state constructs patients as “biological citizens” whose bodies are the sites of neoliberal “citizenship projects”. They argue that “activism and responsibility have now become not only desirable but virtually obligatory” [32] (p. 451) to fulfilling the patient’s idealized role as equal participant. These expectations are partially the product of public and private institutions that seek to discipline citizens by constructing personal responsibility as a moral imperative, and an act of empowerment and autonomy. Salmon and Hall note that the discourse of empowerment “clearly connects with the wider political and cultural emphasis on individual autonomy and rights that is helping the state shed the responsibility for individuals that citizens had come to expect” [27] (p. 55).

## **3. Critiquing the Information-as-Empowerment Narrative**

Assumptions that access to information allows patients opportunities for empowerment and better care are embedded in the construction of participatory patient-hood. However, as Wathen and Harris describe, critics question the clinical value of the information-as-empowerment model



and whether these policies and practices are of greater benefit to the patient or the health care system:

“Accompanying the current discourse on health care reform, in which terms such as *patient empowerment* and *self-care* often appear, is the assumption that health-informed individuals will participate, alongside their health care providers, in a process of shared decision making. Ultimately, the logic follows, informed empowered patients will take responsibility for their health, including managing their health care” [14] (p. 640, emphasis in the original).

The authors note that these assumptions may be inconsistent with patients’ desires to shoulder these responsibilities. Furthermore, their research suggests that access to information alone is unlikely to fill in for important care relationships. In interviews with rural Canadian women about their health information-seeking experiences, they found that participants repeatedly focused on the quality of their relationship to the people they turned to for help and information. They concluded that “the perceived effectiveness of these health information intermediaries seemed to depend largely on how well they expressed care and concern during the information exchange” [15]. Similarly, Salmon and Hall argue that “patients value being given information as a way of building relationships with clinicians and maintaining hope—not as a basis for decision-making” [27] (p. 53).

Several scholars [6,27,33] have argued that the transitions in both discourse and practice are the product of consumer society and its impact on health care. Kopelson [33] maps the transition of the internet-informed patient from nuisance to expert, partner, and manager of their illness and notes that the latest iteration is becoming a prescriptive norm that crowds out other ideologies and behaviors. This is accomplished by creating and recruiting the ideal patient, and portraying those who do not conform as failed consumers who elect not to engage in the enterprising practices of information-seeking and body discipline. The result is a “felt imperative” [34] to enact these behaviors and adopt its goals. Salmon and Hall argue that the idea of empowerment through information is not generated by patients but by those it benefits—providers and, by extension, the health care industry. By not interrogating assumptions about empowerment, providers may be unaware that they are “redrawing the boundaries of medicine” [27] (p. 55) in a way that is burdensome to the patient.

Distinctions between proponents and critics of the participatory e-patient discourse are made more ambiguous by the intersections between the individual patient’s interests and the interests of other stakeholders. For example, pharmaceutical companies benefit from developing and selling the hugely expensive drugs required to treat MS, yet patients need and benefit from them. Advocacy organizations such as the National MS Society, which are often focused on raising money for further research, have closely aligned interests with, and often receive funding from pharmaceutical companies, but rarely disclose these relationships [35]. However, their efforts may help develop better treatments. Substantial resources are poured into consumer education efforts, both by the state through public health campaigns, and by the insurance, pharmaceutical, and hospital industry as cost-effective strategies, yet they provide the individual with important information. These industries have embraced the use of social media, in part, to promote a model of

patient-hood that increases their profitability, yet individuals may feel empowered by using social media to engage in their health care.

The argument that the demands placed on the patients in the current political economy are necessarily burdensome is flawed when applied to the more nuanced experience of being a patient. As I demonstrate in my argument, some patients genuinely feel empowered by their increased ability to be more knowledgeable and more participatory in their care, even as they recognize the burdens and constraints placed on them. While there may be little they can do to influence change in an abstract and unwieldy health care system, they can acquire more skills that help them to negotiate it to their best advantage. This paper argues for a most nuanced understanding of using social media to develop and share knowledge and personal experiences. The political implications of greater patient participation—which both challenges and contributes to medical knowledge and practice—remain significant but are increasingly less novel. Looking at the everyday experience of patients that have chosen to enact this role, as this study does, reveals the ways in which the larger cultural discourse of this model of patient-hood are lived.

#### **4. Methods**

This mixed-methods study focused on American women with Multiple Sclerosis who regularly maintained journal-style personal blogs about their lives. Data consisted of three phases: an ethnographic content analysis of 40 blogs ( $N = 40$ ), an online survey of the bloggers ( $n = 20$ ), and an online discussion forum with bloggers ( $n = 9$ ) for a period of 5 weeks, all explained in greater detail below. Chronic illness such as MS requires daily negotiations with often-unpredictable symptoms over the lifespan. I chose to focus on chronic illness because I wanted to broaden the literature about online illness narratives and health discourse. There is a substantial body of work on cancer-related (especially breast cancer) blogs, online communities, and online advocacy and activism that lays a groundwork for the study of online illness narrative [2–7,11,36], but less research has examined different types of illness.

The nature of the internet as a continually-changing forum opens up new perspectives and arguments for methodological and ethical approaches. Because it is a relatively new field of academic study, fewer standard practices have been established for protecting human participants than for traditional fieldwork. A great deal of internet research includes collecting and analyzing content or observing user behavior without individuals knowing they are being included in research. Hutchinson [37] outlined three schools of thought about using personal online content for research without permission, even when it is publicly-accessible: (1) publicly available information is public and therefore should be able to be researched without explicit permission [38,39]; (2) personal information, such as blog entries and comments, while public, are personal and should be treated as private [40–42]; and (3) the Internet is “publicly-private and privately-public” [43] (p. 131) and should be treated with a balanced approach. The blurring between public and private that is characteristic of social media make a strong case for the latter.

This study was deemed by the IRB to be low-risk and I chose to take a balanced approach by making two of the three phrases participatory. This was not simply to address ethical concerns, but also because participatory research was a primary goal of this project. I sought to elicit bloggers’

voices directly, put them in conversation with each other, and ask them to consider specific topics and questions. I determined that the blogs I included in this study, while personal, were intended to be read by a wide audience. In addition to documenting their personal experience, bloggers often wrote about Multiple Sclerosis advocacy efforts, and shared information and advice. There were also some visible interactions between bloggers and commenters, indicating a willing engagement with a public audience. To protect participants' identities, survey responses were anonymous, and the discussion took place on an invitation-only, password-protected platform. Furthermore, I asked discussion participants to choose their own usernames and emphasized that I would use these when I referred to or quoted them individually, as I do here.

Three phases were conducted over a period of three months.

Phase 1. An ethnographic content analysis of 40 blogs. In conducting an analysis of blog content, which included text, graphics, images, and video, I used Altheide's methodology of ethnographic content analysis. This approach involves:

Emergent and theoretical sampling of documents from information bases (including those developed by a researcher, e.g., field notes), development of a protocol for more systematic analysis, and then constant comparisons to clarify themes, frames, and discourse [44].

Following an overall reading of the blogs using this approach, I conducted a more detailed analysis of 78 posts (in most cases, two per blog). These were selected by choosing two dates and analyzing the most recent post.

Phase 2. An online survey. I sent an anonymous online survey to all 40 bloggers from Phase 1 and received 20 responses. With the survey I sought to understand participants' blogging practices and the role blogging played in their lives and experience with illness. I asked respondents to provide an email address if they were interested in further participation and invited all who did to take part in an online discussion forum.

Phase 3. An online discussion forum. Nine bloggers participated in a private online discussion forum for a period of five weeks. This method directly solicited the perspective of the bloggers and provided them an opportunity to connect with other bloggers who write about having MS. Three overlapping themes were explored over the course of the discussion: (1) being a part of the MS "blogosphere" and feelings of connection to other bloggers or other people with MS; (2) expectations of patients by the medical establishment to be participatory patients; and (3) the blend between their online and offline experiences.

I used a grounded theory approach [45] for analysis. This approach allows hypotheses, categories and conceptual codes, and themes to emerge from the data collection and analysis. In this approach, sampling is aimed toward theory construction, not representativeness. I analyzed data using a method of "open-coding" followed by "focused-coding" [46]. I categorized data based on the major themes that had arisen from initial reading of the text and descriptive statistics, such as medical knowledge or interactions with healthcare providers, and motivations for blogging. I then identified recurrent patterns and sub-themes, such as a specific focus on neurologists, or a love of writing.

For the purposes of this article, I limit the analysis of findings to Phase 3 and focus on how bloggers developed and shared medical knowledge and utilized it in their care.

## 5. Developing Lay Health Knowledge

Inevitably, patients are constrained by their need for health care and a relative lack of influence over an unwieldy medical bureaucracy. Facing such odds, they are left with little choice but to navigate their way through the system, advocating for themselves and their families as best as they can. Findings from this study revealed that while the disease itself was most often seen as an unwelcome burden, both the opportunity and necessity to become a participatory e-patient was not necessarily seen in the same light. Most of the discussion participants saw it as providing opportunities for them to feel more in control of their life with illness. Participant “funktymango” wrote, “I want to be a partner in my healthcare. It’s my body, so if it’s down to choosing between two meds (for instance) I want to be involved in the decision-making.” These findings contradict Salmon and Hall’s [27] suggestion that the construction of patient empowerment is not often experienced as such. These participants, at least, did desire to be informed and have the ability and option to influence their treatment. This is perhaps not surprising from a set of participants who were already actively seeking and sharing information online and may be more likely to take this view than people who do not engage in these behaviors. Nevertheless, this finding demonstrates that while interrogating the assumptions and vocabulary of medical discourse is important, as Salmon and Hall [27] did 10 years ago, we need to revisit these questions in the context of a newer media landscape where social interactions online are easy, ubiquitous, and integrated with lived experience. Furthermore, a discourse of empowerment has become even more embedded in our cultural conceptions of health care practice and patient-hood through social media.

While participants in this study saw these opportunities as benefits, they also didn’t feel they had much of a choice if they wanted to be certain they were getting the best care and outcomes possible. Participant “*turtlespeed*” highlighted this contradiction when she stated, “I like being an informed patient but it does make for a lot more work. I guess I kinda feel that it is just part of being a patient. You need to be able to understand what is going on so you can advocate for your care.” Bloggers developed medical knowledge through their own efforts at self-educating, but they also assumed the role of lay expert by choosing to share and discuss this information on their blog and interacting with others online. Many of the participants considered themselves educators and translators of complex medical information and blogs provided a wide-reaching forum for their work. As a result, they saw themselves as having a responsibility to readers to provide accurate and up-to-date information that was supported by scientific research. In addition to carefully crediting sources, bloggers were careful to make clear distinctions between research-based expert knowledge and their personal experiences.

In the discussion, participant “sheltiemom” described the benefits and risks associated with using the internet to get information when she wrote, “we do have to be careful because while the internet can be helpful there is alot of Crap info out there also. It seems everybody has some crazy cure for MS.” In response, “funktymango” wrote “This is so true...I think this puts some

responsibility on us as MS bloggers/bloggers about MS to make sure the information we give is accurate.” Similarly, “sherri” warned:

There are bloggers out there who do their own “research” and draw their own conclusions, then go and post it as medical based knowledge. This is very dangerous. If a newly diagnosed or very naïve person reads the information as legitimate, they might face some problems....I think that being a personal blogger carries some responsibility but not near as much as someone who is blogging and calling it research...those research based bloggers should be held to a much higher level of responsibility and standard.

Personal accounts of a blogger’s experience were seen as equally helpful, if not more so, than research-based information. For “sherri”, other bloggers’ personal experiences were the most helpful to her because they supplemented the information she received from her doctor or researched herself, and allowed her learn from others’ experiences with the disease. She wrote that on some of the blogs she read:

...there was no declaration of fact—only personal stories. In my mind, these were the best sources of information for me. I could compare what I was reading on personal sites to research or things my [neurologist] had said, which helped me understand the disease.

For her, both kinds of information were seen as equally valid and complemented each other. Making a clear distinction between professional and lay expertise highlighted this symbiosis, rather than simply privileging professional expertise. Developing knowledge about the biological functions of MS provided a context in which to place the embodied experience of the disease, but the most intimate knowledge of the disease came from living with it. Bloggers often described daily experiences—descriptions of symptoms, notable incidents like a fall, accommodating daily routines due to fatigue, or pushing oneself too hard—rather than, or in addition to, research-based information. This embodied knowledge was acquired over time, and linked with the medical knowledge they learned from formal sources.

Not surprisingly, health care providers, specifically neurologists, played a significant role in bloggers’ lives, even when actual encounters were infrequent. This significance was not only important to the physical treatment of the disease, but to their emotional experience as well. Encounters and relationships with medical providers were most often described in polarized terms: either positive experiences or negative/contentious experiences, suggesting that these relationships are highly charged. These important relationships were negotiated between what bloggers expected of themselves as patients and what they expected of their neurologists. In addition to wanting to be knowledgeable enough to be part of decision-making about their care, they wanted doctors who considered and respected their knowledge. This is consistent with Wathen and Harris’s [15], and Salmon and Hall’s [27] findings about the importance of the quality of relationships in receiving health information.

Bloggers’ ability to fill the role of self-advocate and partner in their care was not one-sided. It was also partly contingent on healthcare providers meeting the patients’ expectations. The bloggers

expected their doctors to respect them as people, treat them as knowledgeable patients, and to care about them. Likewise, their satisfaction with healthcare providers was largely dependent on how well providers fulfilled these expectations. When a provider did not, bloggers usually found a new one who did. While most bloggers assumed that their neurologists were well-qualified, those who did not meet expectations for a caring and respectful relationship were usually described as having a patronizing attitude and resistant to patient input. While bloggers wanted to be considered a partner in their care, they also sought to maintain the distinction between professional expertise and the lay expertise they developed from personal experience and wanted their health care providers to be more knowledgeable and able to guide them in decision-making.

Participant “ellie”, a former physical therapist, said that she was “treated [respectfully] as a person with knowledge” by doctors most of the time. She enacted the role of participatory patient by maintaining a chart of her health, which she brought with her to doctors’ visits. However, she wrote, “even though I am and want to be a knowledgeable partner I need him to be a caring MD”. She described a recent appointment, in which her doctor was attentive and supportive, and wrote “he was my physician and I was his patient...and that’s what I needed at that time”. Likewise, “katewj” also described feeling the need to direct her own care: “my treatment is very much ‘in silos’ and I have to be the communicator who thinks to ask one specialist about the effects generated by another”. She also wrote “I want to be an empowered, informed patient AND I hope for doctors who are more informed than I.” Several bloggers described feelings of satisfaction from being included in decision-making, such as “sherri” who wrote, “he gives me his opinion, allows me to research things, and then together we make decisions about what is going to be next”.

In contrast, participant “sheltiemom” described a neurologist who had a “‘go home sit on the couch and die’ attitude”. Fortunately, she was able to switch to a doctor who was more proactive and receptive to her participation. A few bloggers, however, had either not been able to switch to a new neurologist or had switched but still not found one they were happy with. “grace2wheel” described “an endless battle with doctors who have too much power over my access to medical care as well as the all important disability insurance. To be blunt, I dread seeing my neurologist.” “marie” wrote that she been to three neurologists in her local area:

The neurologists have been mostly arrogant and close-minded, needing to be in control and, locally, out of date with treatment protocols. Very threatened by any suggestions of knowledge by me, the patient....It is very disheartening, as a patient with a chronic disease, to feel you are not understood or respected as an intelligent, informed adult.

While patients are enabled to be well-informed about their illness, the inherent power structures in health care still limit their role to contributing information to the provider’s expertise. The extent to which their knowledge, experience, and desire can help direct their care, however, is partly contingent on their medical providers sharing their ethos.

## **6. Limitations of the Study**

Much internet-based research, particularly early studies, relied heavily on unobtrusive observation by researchers and while observation is a rich source of data, I believe that connective

media calls for participatory methods. With this in mind, I solicited the perspectives of bloggers directly in order to better understand their experiences as they saw them and chose to write about. In addition, by using three distinct methods (an ethnographic content analysis, an online survey, and an online discussion), I approached the topic from multiple vantage points.

As with all methods, however, these three had some limitations. In studying public blogs, I chose subjects who openly share their personal viewpoint. This means that my findings are specific to the small minority of American women with MS who blog publicly, and don't represent the hundreds of thousands of women with MS who do not. However, drawing on the support of literature about online illness communities [1–11], I found similar themes about living with illness (such as describing the disruption caused by illness and strategies for working around limitations). It is reasonable to assume that some commonality is shared by bloggers and non-bloggers alike.

As public bloggers, these women may be more comfortable sharing their thoughts and stories and be predisposed to participate in a research project compared to private bloggers or non-bloggers. A certain amount of self-selection probably contributed to the willingness and enthusiasm of the nine bloggers who elected to participate in the online discussion. Nonetheless, this study adds important voices and the themes could be extrapolated to other contexts.

## 7. Conclusions

Being a participatory patient who uses digital tools to acquire, share, and develop knowledge is neither inherently empowering, nor does it shift an undue burden onto the patient. It offers opportunities to feel empowered by acquiring information and connecting with others. It is also undeniably a laborious practice that has become a more common expectation by both patients themselves and the health care industry to take full advantage of the large amount of information made available through easily-accessible networks. In this study, it is clear that the practice of utilizing digital and networked tools, is accompanied by other social practices such as fostering community and mutual support, and negotiating medical relationships.

Overall, the bloggers viewed the idea of being knowledgeable about the disease and having an active role in decision making and treatments positively. They also viewed it as their responsibility if they wanted to feel equipped to engage with their medical providers and make decisions. Participant “sheltiemom” implied that ease of access to information via the internet did place some responsibility on the patient when she wrote “I don't think our doctors expect us to be educated but most probably appreciate it if we are. In this world where info is easier to access on the internet it is important for us all to be our own advocate and be informed.”

Americans continue to go to their health providers for information first [13] and many view their use of the internet to find information as supplemental to their primary care [16]. In this study, participants talked about conducting online research in preparation for a health care visit. This neutralizes claims that access to health information de-centralizes health care practice or, as Health 2.0 proponents suggest, revolutionizes it altogether. Rather, using the internet and social media to acquire, share, and create health knowledge expands the reach of information. It increases the participation of some patients and further normalizes resistance toward patriarchal medical practice as a whole, but is unlikely to unseat primary health care providers as central figures in care.

The findings of this study demonstrate that blogging is a simultaneously empowering and disciplinary set of practices. The same mechanisms reproduce these practices, namely authoring public narratives about lived experience with illness and the consumption, generation, and dissemination of knowledge by patients. While blogging reproduces the discourse of self-responsibility and body governance, it also gives voice to experiences, which can empower the patient to challenge the dominant power structure upon which contemporary medicine is constructed and redirect narratives of illness and disability. Likewise, the practices of self-educating, producing experiential knowledge, reporting data, and disseminating knowledge can provide the patient with information that can be used to help treat their condition and which may give them a sense of greater agency.

In enacting these practices both *by* blogging and *through* blogging, these study participants create and shape a mediated space through which to practice participatory patient-hood. Critical concerns of how political, social, and cultural norms are scripted onto the body, suggest a passive patient, unaware or unconcerned with the forces working on her. Feminist theorists have sought to counter these assumptions by calling attention to how these forces are experienced [6,47]. Indeed, the participants in my study were very much aware of the interest in their bodies by a number of institutions: a health care system that simultaneously tries to treat, care for, regulate, profit from, and deny care to them; a state that reluctantly supports them with often too-meager resources; and a political and socio-cultural framework that constructs them as disabled and generates and reproduces a discourse of illness within which they negotiate their lives. This study has revealed that participatory patient-hood is contradictory: the burdens and expectations that are placed on them may be welcomed by patients for whom more information helps them manage the everyday realities of living with chronic illness and navigate the systems in which they have little choice but to participate.

### Conflicts of Interest

The author declares no conflict of interest.

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# “Maternal Devices”, Social Media and the Self-Management of Pregnancy, Mothering and Child Health

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**Abstract:** In recent years the smartphone has revolutionised lay people’s management of health and illness, particularly in regards to pregnancy and parenting. This article analyses smartphone applications, or apps, and social media platforms as mediating technologies which act as performative devices. These devices encourage particular enactments of subjectivity and technologies of the self which combine the expert patient ideal with ideologies of mothering. Some apps and social media can be disciplinary and invoke biological responsibility in various ways including the monitoring of specific behaviours via “push responsabilisation”. Apps claim to allow for greater convenience, connectivity, flexibility, efficiency, and what will be characterised in this article as the “tidbitisation” of information. This article suggests the ways in which health-conscious pregnant or maternal subjects are likely to view apps and social media sites as a means to improve and monitor their pregnancies, health, and their children’s development and health.

Reprinted from *Societies*. Cite as: Johnson, S.A. “Maternal Devices”, Social Media and the Self-Management of Pregnancy, Mothering and Child Health. *Societies* 2014, 4, 3306350.

## 1. Introduction

The smartphone revolution over the past five years has had a significant impact on our lives, influencing our daily activities in varied ways. One of the most important influences has been the continuing technological expansion of the management of health and illness, which is now incorporated into many people’s smartphones via a range of applications, integrating anything from calorie counters to exercise trainers. Smartphone applications (“apps”) and social media platforms are important elements in the rapidly changing environment around pregnancy and the transition to first-time motherhood. Despite much theoretical research highlighting significant changes in digital health technologies, studies analysing these technologies, their possible implications and the experiences of users are few.<sup>1</sup> This article begins to address this gap in the literature by analysing smartphone apps and social media platforms that are coming to play a role in the everyday practices of the maternal subject.

Pregnancy and mothering are no longer seen as simply a reading assignment [6]. In the context of an increasingly digitalised world, the transition to first-time motherhood is now an embodied project which encompasses digital health, responsible biocitizenship, accessing the internet as a source for support and advice and the use of a range of new devices, changing the way pregnancy and mothering are understood and practiced. Together, these developments promise to make

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<sup>1</sup> Specifically there has been very little research on the use and impacts of smartphone apps and social media as they are used as part of pregnancy and parenting practices. At the time of writing there were very few academic papers on this topic [1–5].

maternity a self-calculable exercise in data management. In this article, I consider how apps and social media platforms organise parenting practice and have the potential to produce new experiences of pregnancy and motherhood. In contemporary culture's emphasis on choice, individualism and empowerment smartphone apps and social media are an increasingly important object of analysis, through which we could study changing relationships towards technological devices and new patterns of behaviour, understood in this article as technologies of the self [7–9].

## **2. Maternal Subjects as Expert Patients**

The personal management of health is an avenue through which individuals can embrace their duties and responsibilities as “good citizens” and ethical selves [10–12]. In an age of increasing digitalisation individuals have unprecedented access to a huge range of health information and one of the consequences of this access is that one feels the imperative to present as, or be, an “expert patient” [13–15]. The expert patient is expected to negotiate their healthcare with careful research and self-education. Research on the expert patient is most often focused on patients with chronic disease such as obesity [14,16] or cancer [15]. It has, however, important implications for understanding women's experiences as maternal subjects, particularly their use of technology in the management of maternal and foetal health.

Maternal subjects, as expert patients, are expected to adopt a highly reflexive, intentional and carefully researched orientation to the consumer market catering to pregnancy and parenting [11]. This expectation is combined with ideologies of motherhood, such as intensive mothering. According to Hays, intensive mothering: “requires not only large quantities of money but also professional-level skills and copious amounts of physical, moral, mental, and emotional energy on the part of the individual mother” [17] (p. 4). Immediately we recognise the dictates of expert patient and intensive mothering share many features and thus combine to form a particularly powerful technology of the self [7–9]. The intertwined roles of mother and expert patient therefore serve to emphasise personal responsibility over making the “right” choices for your child. This is a central consideration in this article as I analyse how the development of specific apps impacts on the relationship between the expert patient ideal and contemporary mothering ideology.

## **3. “Being-for-Intimate-Others”**

A growing body of literature reveals the various ways the foetal and infant body are positioned in popular media and medical and public health discourses in order to encourage maternal responsibility [18–22]. In neoliberal society, women turn to a range of technologies and systems of expertise and guidance in order to manage the risks, pressures and challenges characteristic of the transition to first-time motherhood. In doing so, women undertake specific pregnant and maternal practices to ensure the health and well-being of the foetus and infant. These practices can be defined according to Foucault's [9] notion of technologies or practices of the self. In Foucault's account, technologies of the self are not coercively directed but are encouraged by the enhancement and pragmatic actualisation of general moral goals and aspirations which may include desires, pleasures, happiness and good health [23]. Technologies of the self therefore reveal the multiplicity

of ways in which dominant discourses may be enacted, resisted, negotiated or differentially embodied in the individual's ongoing ethical project of the self. This analytic frame enables us to identify variations in how individuals or groups of individuals might constitute themselves as subjects of given moral injunctions.

With the growing standardisation of medical technologies and interventions, pre-pregnant couples, pregnant couples and parents actively consume and demand these in order to optimise outcomes, in the process incorporating risk avoidance as a technology of the self. Maternal subjects may therefore embrace medicalisation as part of their desire for the best possible outcomes in reproductive, foetal and infant health [8,24–26]. As more technologies offer more opportunities to optimise foetal health outcomes, “the choice not to choose” appears selfish as this stands as a denial of “the best care” available [27]; [28] (p. 2). It is at this juncture that the responsabilisation of individuals in the neoliberal context becomes something more for maternal subjects as they are not simply acting for the self but also for the unborn “other”. Thus, I argue that responsabilisation for maternal subjects is both gendered and double-pronged; this is not simply neoliberal responsabilisation as we know it, but responsabilisation of the self-for-others; “being-for-intimate-others”. This gendering of responsabilisation is also implicit in the ideology of intensive mothering which argues that mothers must do everything possible, including self-sacrifice, for the sake of their children [17].

The immersion in numerous media forms aids in the self-education of individuals and also allows them to engage in “biomedical self-shaping” [29] (p. 446) where patients actively make choices regarding their genetic and corporeal responsibility, acting on and disciplining themselves according to expert recommendations.<sup>2</sup> I attempt to move beyond Rose and Novas's [29] work on “biomedical self-shaping” to demonstrate the ways in which devices such as smartphone apps and social media could be utilised by pregnant women and new mums as they engage in the project of first-time motherhood. I have already suggested that the convergence of the ideologies of intensive mothering and the expert patient ideal work to create a powerful technology of the self for maternal subjects. I consider whether we can now add the technology of smartphone apps to this nexus, potentially attaching new rules, meanings and dynamics to the ethical project encompassing pregnancy and motherhood (and instituting these rules through their incorporation into devices). Are smartphone apps and social media platforms simply disciplinary devices, or do they do something more? Are they also performative and if so, what sort of pregnant or maternal subject are they producing? Do women utilise social media and apps to engage with the ideal of the expert patient, the intensive mother or some other ideology of mothering?

#### 4. The “Device-ification” of Maternal Subjects

The integration of apps and other smartphone technologies into everyday life, routines, and definitions of the self illuminates the ongoing dynamic nature of biological citizenship, representing a new development in self-health practices that adherence to self-help guidebooks alone would not afford in the same sort of way. This article explores some of the possibilities

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<sup>2</sup> Descriptions of self-identity increasingly include “biologically colored languages” [30] (p. 73) which demonstrate active relationships with medical and scientific authorities and products.

associated with this notion of “device-ification”. Apps and social media platforms are able to be integrated into every-day life via the portability of smartphones, tablets and other mobile devices. The employment of such devices suggest a specific way of producing (self-)knowledge of the pregnant body and offer ways in which women can understand or define their pregnancies and/or mothering practices. They could also work to encourage women to evaluate themselves according to various prenatal norms thus allowing them to measure how good or bad their specific practices are deemed to be.

These new technologies are not simply an extension of more static forms of self-help (such as guidebooks) as devices or technologies of the self, but represent a transformation of these. This material development is important. It allows people to relate to what used to be a book via a new set of instructions or practices through a device in a variety of locations and even whilst multitasking. This changes the relationship of the body to sources of authority or information, and specifically, the “pushiness” (the functionality of push notifications) of some devices creates new relationships to technology and advice. These changes suggest the possibility of new forms of subjectivity or enactments of pregnancy and mothering. Therefore apps and social media are not simply sources of information, but also act as performative devices in that they prompt or provoke women to act on and through their bodies via these devices.<sup>3</sup> These devices are designed to help women (and their partners) to engage in their pregnancies and parenting in particular ways.

The assemblage of devices specific to pregnancy and motherhood provide a range of detailed techniques to monitor, manage and assess the body and therefore play a role in the ongoing project of motherhood. Women are encouraged to engage with a variety of maternal devices as a way of generating and/or practicing technologies of the self, and smartphones and smartphone apps are one specific genre of these devices. Other maternal devices include: dietary charts, exercise regimes, calculators for pregnancy weight gain, charts for foetal movements, blood sugar level testing and breastfeeding charts. These “maternal devices” prompt the user in particular ways, making suggestions and connections and encouraging them to invest in, make sense of and act upon particular principles. These devices produce a reflexive subject concerned with health and lifestyle and are geared towards practices of active health, lifestyle, self-assessment and self-education.

Digital health technologies (including apps) are a form of mediating technology which shape meaning and create new spaces for health and responsabilisation, and at the same time, reshape individual’s understandings of norms and standards. Digital health technologies are largely consistent with preceding modes of neoliberal governmentality, but their most significant feature is that they extend these modes of responsabilisation into new spaces and practices and forms of calculation. By critically analysing a number of smartphone apps and social media sites, this article draws on and challenges Foucauldian theory on social relations and practices of the self. An analysis of these technologies poses questions as to how pregnant women and new mothers become particular ethical subjects, because as Brown and Webster [32] (p. 7) argue “technologies are

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<sup>3</sup> The term “devices” is adopted from Kane Race [30]. In his research on hydration practices, Race reappropriates Michel Callon and colleagues’ [31] use of the concept “market devices” in order to consider how certain online functions, including self-assessment tools, act as calculative devices. These devices are connected to technologies of the self already implicated in biocitizenship.

always socio-technologies". By assessing the kind of work these devices could encourage and the multiplicity of ways women could potentially engage with them, one is able to consider a wider range of the different approaches to embodying and negotiating the moral injunctions and forms of advice women encounter in the transition to first-time motherhood.

## 5. Background and Methods

The interview data used in this article was collected as part of a qualitative study on the changing nature of pregnancy and mothering practices in the context of new media, and how technologies may be enabling new spaces for experiential learning and health responsabilisation. This empirical research formed the basis of my PhD entitled "On a Tightrope? Technologies of Motherhood in Neoliberal Society". This project received ethics approval from both the University of Sydney and the Royal Prince Alfred Hospital (RPAH) in December, 2011 (Protocol No X11-0334 & HREC/11/RPAH/526).<sup>4</sup>

The use of smartphones and apps emerged as a theme of interest late in this research project. The constant mention of various apps by the participants prompted me to examine a number of key pregnancy and parenting apps in terms of the discourses they mobilise and their functionality. This examination is the focus of this article. I was also able to draw on the characterisations from participants in attempting to understand the affordances of apps and the role they may play during both pregnancy and new motherhood. These characterisations are central to my analysis and interpretation of these technologies and devices.<sup>5</sup> Although the interview data collected on the themes of digital health technologies and social media was not exhaustive, I argue that it is important in providing a new methodological approach to research in this area. As the theme of this special issue is the development of critical approaches to digital health technologies I argue that this qualitative research offers a new approach. Rather than focusing on the devices or technologies themselves, the focus is on how it is that people interact with these devices and create new relationships, practices of gathering information and accessing information as a result of these interactions. Therefore, rather than offering detailed insight into my specific participants' use of smartphones and apps, this article provides an analysis of several significant convergences in software, technologies and practices of the self. The significance of this analysis is that it provides a platform for further research (including more detailed empirical research) in this area.

In this article I analyse smartphone apps and social media sites using a discourse analysis approach. Two theorists using a Foucauldian model of discourse who have strongly influenced my approach to discourse analysis are Deborah Lupton [33,34] and Jane Sunderland [35]. Both of these theorists have applied critical discourse analysis to extensive fields including public health and

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<sup>4</sup> The interviews occurred during January and September, 2012. Ten of the twelve participants were interviewed twice: once during the third trimester of their pregnancy and again when their babies were 3–7 months of age. The majority (20 of 22) of the interviews took place in the participant's home, with the remaining two interviews occurring in a neutral public location chosen by the participant. In both cases, this was a private room on campus at the University of Sydney.

<sup>5</sup> This development was particularly important in the context of my broader research aims which focused on understanding the different ways women negotiate the transition to first-time motherhood.



parenting literature. Their applied use of Foucauldian theories have provided analytical approaches focusing on interpreting the relationships between social knowledge, discourse, power and existing institutional dominance.

It is important to analyse smartphone apps and use of social media sites as forms of discourse, as “different ways of structuring knowledge and social practice”, or “seeing” the world [36] (p. 3). But more than simply providing new ways of “seeing”, these devices also prompt and concretise specific ways of acting, at the same time, shaping and organising the gendered discourses of parenting and mothering in particular. For an increasing number of people, apps and social media have been integrated into daily life which we can view as an extension, and digitalisation, of the expert patient role, shaping the everyday management of illness and health and social processes associated with them. Apps and social media, through their broad range of language and utility, influence gendered identities and relations, suggesting a particular representation of mothering (and fathering). This article will examine how certain apps reference, implicitly or explicitly, ideologies related to pregnancy and mothering, such as “intensive” mothering and “helicopter” mothering, and the expert patient ideal.

## **6. Pregnancy: Is There An App for That?**

Many apps for pregnancy (and mothering) are temporally tailored, meaning that the app is calibrating the pregnancy in terms of “stages” and “time” and encouraging the user to connect with her pregnancy as an exercise in foetal development. Temporally tailored apps often also include a notification function which sends regular (usually daily or weekly) updates to the user. Many pregnancy-specific websites also send regular temporally tailored updates via email and these emails function in a similar way. This adds a new level of awareness to pregnancy where the updates are “pushed” to the user rather than the user seeking this information out. The updates can include a variety of information but will usually include details on foetal development as well as what the pregnant woman should expect that week. They can also include pieces of advice for the mother such as foods to avoid and exercises to engage in, possibly invoking behavioural change as a result. The *Dr Miriam Stoppard Pregnancy* [37] app includes weekly reminders for the user to watch video content which includes Dr Stoppard giving them “personalised” advice for each week of their pregnancy, and to record notes on their experiences and to update the “Bump Tracker”, a feature which allows women to use their smartphone to create a gallery of images of their growing “bump”. From this perspective, the pregnant woman is made to be constantly aware of her pregnancy and from the first signs of pregnancy, to interactively engage with her body and her foetus as an exercise in both health management and bonding.

Apps are marketed as convenient because they allow access to information anytime, anywhere, but they are also imposing, pushing information to women at regular intervals that they may otherwise avoid or fail to seek out of their own accord. In this sense, apps are not simply temporally tailored but involved in the organisation of women’s temporality through the mechanism of the push notification. Therefore these devices create a new form of awareness and responsabilisation: “push responsabilisation”.

Many women access temporally tailored emails or apps for the supposed convenience of regular updates. Therefore, not only is content important, but the accessibility and portability of these apps can be viewed by users as essential for today's busy lifestyles. These sentiments were echoed by the women interviewed in my study. When asked about emails or apps they receive or use, their descriptions focused not just on the content, but the portability, accessibility and integration into a busy lifestyle:

Emily, 37 (prenatal interview): "I would kind of flick through, say something, he'd [her husband] be interested, grab it, read it, put it down. But I think they're the kind of, like app things are good, 'cause you can update them little things and try and talk about them...little bits of information at the right time".

As this quote indicates, apps also appeal to individuals in regards to the digestibility of information they contain—rather than searching through an entire chapter or pamphlet or website, apps provide tidbits of information for pregnant women, mothers, and partners. Apps and email updates allow for what I characterise here as a convenient and accessible "tidbitisation"<sup>6</sup> of information, as the following quotes indicate:

Simone, 32 (prenatal interview): "so every week I receive a follow-up of where the baby is at in the womb and maybe what's going on with the pregnancy...that was really helpful, 'cause just a few hints, like a small newsletter, not too long to read, just enough".

Emily, 37 (prenatal interview): "I mean, it's [the regular app update] very brief, basic. But no, no it's been good. Lots of little tidbits along the way as opposed to you sit down and read a chapter [laughs]. So, which is kind of good."

Diana, 29 (prenatal interview): "I've had...weekly email updates and that sort of thing, um, so little tidbits of information as I go, just about how the baby's going and things that I might want to aware of...they're good because they're just little bits of information...they're not too much, and there's usually not enough to freak you out or be confusing or anything".

Smartphone apps and social media such as Facebook and Twitter offer mums, particularly new mums, also offer a novel form of socialisation or communication whilst staying inside the home, even whilst multitasking, as Jenny states in the following quote:

Jenny, 41 (postnatal interview): "And, actually something else that's probably, possibly revolutionised um breastfeeding and mothering is the I-phone...I can be here for a long time sometimes [feeding the baby], which is why the I-phone can be useful, for emails or looking at the Facebook or the Twitter".

Other mums in my study also spoke of the convenience of their smartphone and many used Facebook and emails on their phones regularly in order to check for events related to their mothers'

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<sup>6</sup> This word is taken from the interview participants' use of the word tidbits (as used by Emily and Diana, above) and other similar characterisations of information as small and accessible by other participants.

groups or to ask questions about their baby. So for new mums the smartphone offers an extension of their social life and allows them to continue communicating with friends, even whilst being housebound or involved in domestic tasks specifically related to mothering.

Therefore smartphones and apps are “revolutionising” the experience of pregnant women and new mothers, as they claim to generate convenience, connectivity, flexibility, efficiency and the tidbitisation of information. These apps are often sold as tools of convenience although this “convenience” at times involves greater work and expectations than the alternative (discussed in more detail later). In addition, women may view new technologies like apps as empowering in that they offer women new feelings of control over their bodies and give them a particular knowledge of their pregnancies and the behaviour of their baby/babies or children; although having more knowledge could also equate to engaging in a greater deal of physical labour and “emotional work” during pregnancy and motherhood [38]. Because the female body has traditionally been seen as leaky, uncontrollable, open and permeable, new technologies appear to allow women to attempt to reassert control via diet, exercise or the gathering of information.

## 7. Apps and Social Media

Facebook is a high-traffic social media platform which can be accessed on smartphones via the Facebook app or the Facebook mobile site. There are many uses for Facebook, including social connection, joining shared interest groups, virtual people watching and social surveillance [4]. Facebook therefore offers a variety of social networking options and potential for the maintenance and formation of social capital for both pregnant women and new mums [39]. The social support networks parents access have therefore expanded to include online communities such as social networking sites. Declaring one’s pregnancy online could enable women to connect with other expecting mums, bonding and sharing in experiences, leading some social work researchers to argue the social value of social media. For example, Bartholomew *et al.* argue: “Facebook serves an important function in the acquisition of social capital and social support resources, which are beneficial at the transition to parenthood” [1] (p. 464). Facebook may also serve as a site through which individuals seek to validate their identification as parents. In this sense, Facebook provides a new form of comparison of social and cultural expectations surrounding pregnancy and motherhood. The calculability of “likeability” on social media forums like Facebook has the potential to transform online “performances” of mothering into specific forms of social competition.

Devices and social media such as Facebook also have the potential to transfer the pregnant woman or mother’s virtual identity onto her baby. In this sense, the virtual identity of the baby works to simultaneously deflect attention from the mother (as she hides behind the scenes like a puppeteer) and projects the mother’s work (of being a good mother) and worth (measured through her baby), rendering these visible. This presents a digital performance of what I call the “puppeteering mother”. In wanting to project her baby, instead of herself, she also encapsulates “being-for-intimate-others” where this projected version of self-centeredness or self-worth, of presenting the baby as “my measure” reconfigures neoliberal self-centeredness to include the projected “other”. By representing their baby through digital platforms mothers are able to accrue self-worth that might otherwise be difficult to attain or is normally accrued through other social

forums. In particular, the “likeability” feature makes these digital projections so interesting because self-worth is rendered calculable.

Facebook may be one of the social communities in which women and their partners first announce their pregnancy<sup>7</sup> and where they may share ultrasound images, their experiences during pregnancy such as dietary and fitness dilemmas, as well as their excitement at the impending arrival of their baby. In this way, babies (or foetuses) have an “online birth” prior to their physical birth. This online presence may continue as the child’s birth is announced on Facebook, along with other key milestones. As social media gains more importance in people’s everyday lives they are increasingly likely to announce life events online, in the process altering the dynamics of social relations.

Rose and Novas [29] (p. 440) describe new forms of citizenship in collectives organised around specific medical conditions and/or knowledge as “informational bio-citizenship” and the new electronically networked individuals who are linked to such communities as “digital bio-citizens”. Deborah Lupton goes one step further in describing “the digitally engaged patient” [40] (p. 256) who embodies digital health technologies to engage in self-care and self-monitoring. I argue that social media creates a whole new set of relationships for the “digitally engaged” maternal subject which involve the publicising of foetal and child development via a so-called “friendly” spectacle. This publicising enables others—a public of virtual friends and acquaintances—to become directly implicated in what was previously a very personal sphere of intimacy. This new spectacle is also interactive and allows others to engage with the online foetus by commenting, liking or sharing images or statements. This suggests a new way of quantifying or measuring social status.

Using the ultrasound image in such a way provides a social rather than medical way to view the insides of women’s bodies as well as the foetus/baby. This new social ritual also reinforces foetal individuality and personhood in a very visible and public way. This not only occurs via the ultrasound image, but also via regular profile updates and comments. The foetus has developed its own digital social identity and status before it is even born—some new parents even create Facebook profiles for their new babies—and a digital footprint of pregnancy and mothering is also created.

One software designer has taken advantage of this new trend by creating an app which allows the user to do more than just post an ultrasound image. *Pimp My Ultrasound* allows users to “have fun” with ultrasound images: “you can have several months of entertainment and create everlasting memories” [41]. The app enables you to add text bubbles, headgear including tiaras, bows, baseball cap or football helmets, accessories including a credit card, microphone, guitar or martini glass and picture frames. In this way, the app allows the user to pick and choose certain items in order to give the foetus a gender and/or personality.

The app is purported to provide harmless fun for parents-to-be but could also play a role in early social shaping, particularly gender shaping as many of the accessories are gender stereotyped. “Playing” with the ultrasound image is performative as it encourages a particular type of bonding and attachment with the foetus. It makes the foetus “real”. It sexes the foetus. The foetus is no

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<sup>7</sup> The list of profile options on Facebook now even include “Expected: Child” and the unborn baby can also be given a name in this profile.

longer an abstraction, but a baby with an imagined personality. “Babyhood” is created when the image is “baby-ised” into a dancing, sleeping, sporty or thumb-sucking individual. Technology and the human imagination combine to form the “cyborg foetus” [20,28]. In the following quote, Jenny discusses how her baby’s personality develops in her imagination after the sexing ultrasound:

Jenny, 41 (prenatal interview): “finding out that she was a girl probably changes things dramatically...because then she starts to take on a personality in your own mind...first of all there’s those flutters and it’s just really exciting because it’s like more reinforcement...that it’s there and happening. And then when your, your belly’s big enough to start to see rippling and you start to give it, the baby, more of a type. Like active or whatever”.

Ultrasound images function as a form of “mediated realism” and the foetus is imagined into action—playing a guitar, giggling, thinking or resting. In addition, by “playing with” ultrasound images through apps like *Pimp My Ultrasound* particular gendered expectations for the mother and father, as well as gendered performances from the baby boy and/or baby girl are articulated [42]. This is part of the “fetishization” of the foetus, as Petchesky states: “Indeed, the very idea of “bonding” based on a photographic image implies a fetish: the investment of erotic feelings in a fantasy” [43] (p. 277). This fetishising of the foetus works to create both baby and mother. In a press release for an Australian 3D/4D ultrasound company, it is also suggested that the bonding experience of a 3D ultrasound helps to responsabilise women to care for themselves during pregnancy: “He [owner, Ray Jordan] adds that studies have shown that after using 3D ultrasound mothers took better care of themselves” [44]. It would not be unreasonable to suggest that apps like *Pimp My Ultrasound* may also help to responsabilise women by encouraging them to bond with their foetus, assign a gender, and create a “social identity” for them. Other apps also “baby-ise” via real-life images of foetuses attached to detailed descriptions of current foetal development. These apps are now part of the (bio)technological environment which constructs the contemporary foetal identity and meanings surrounding it.

## 8. Sprout Pregnancy

*Pregnancy Sprout Lite* [45] is temporally tailored and encourages users to track their baby’s progress. This app allows social media interaction where users can share progress on Facebook and “Email notes and development information”. It is both strange and fascinating that *Sprout* enables the user to upload 3D images of what her foetus would look like at various stages of her pregnancy, complete with a personalised name (see Figure 1, below). Miriam Stoppard’s app [37] has a similar feature which allows the user to view the foetus’ development throughout the pregnancy, but it goes one step further by allowing the user to imagine what it is like to be the foetus in her womb. The user can record sound clips and play them back with distortion to imitate the sound of her voice to the baby in the womb. It also allows the user to take photographs which are distorted according to how the baby would view the image through their developing eyes. In this way, the foetus is not only personalised, but the mother is encouraged to embody the foetus from a sensory perspective.

The user of the *Sprout* app can also share her baby's kicks on Facebook and later, she can post contraction information during her labour. These features “baby-ise” the foetus and the social media connectivity gives the *Sprout* app a new layer of meaning by socialising the unborn baby and its activities, allowing other Facebook users to characterise the unborn baby, “like” the images and/or follow its progress before it is even born. This means that the app functions to extend the pregnancy experience beyond the pregnant subject making the pregnancy a more social event, just as 3D/4D ultrasounds and the *Pimp My Ultrasound* app do.

**Figure 1.** Screenshot from *Sprout* app which reveals a very humanised image of a foetus who appears to be sleeping and sucking its thumb. Despite not being born yet, the foetus has already been named Emma. Source: Med ART Studios (with permission to use image).



The *Sprout* app also includes a “Doctor Visit Planner” which encourages the user to take up the role of the expert patient with functions such as “Create a list of questions for your doctor” and “Record your doctor’s answers” [45]. The “Doctor Says” section encourages healthy behaviour via different recommendations which relate to diet, exercise, symptoms and concerns. Miriam Stoppard’s app [37] also provides information on “Looking after your body and mind” and detailed information on diet which is presented as primarily for the sake of the baby, rather than the mother. This section of the app is entitled: “Eating for my baby” and presents healthiness as central to “being-for-intimate-others”. By connecting the app’s functions to medical authority and expertise meaningful connections are made between medicine and the organisation of the body. Ettorre [7] (p. 246) developed the term “reproductive asceticism” to represent the ways in which pregnant women are expected to manage, monitor and control their bodies for the sake of the foetus. I argue that comprehensive pregnancy apps like this one represent a digitalised organisation of reproductive asceticism.

Encouragement to perform the expert patient role and ideal, healthy citizen is also invoked via *Sprout's* Kick counter to record baby's kicks, the Contraction timer to reliably record contractions, and the weight tracker which ensures regular recording and tracking of weight gain during pregnancy. Each of these features increase awareness of the pregnancy, make the app performative and also allow the app to extend beyond the pregnant subject, to function as an extension of the available spaces for health responsabilisation and recording of relevant data, playing a role in the development of maternity as an exercise in data management.

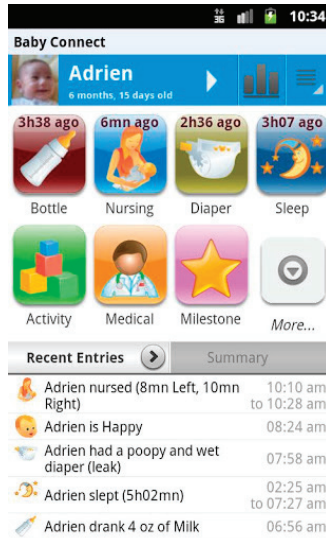
## 9. Baby Connect

As I have argued, apps are a mechanism with which individuals can pursue the “will to health” [46] as they offer possibilities of improving, reshaping, enhancing and optimising pregnancy and motherhood. During my research I found that some women approach pregnancy and motherhood as a project. If such is the case, this new range of tools and devices offers them new ways to professionally and technically adapt to such a project. The significance of these technologies lies in their extra level of functionality where they become tools which women engage with in order to enact or embody the “good” mother, the “yummy mummy” [47] or ideologies of mothering such as intensive mothering [17]. Devices such as smartphone apps offer mothers a new way to implement different forms of parenting, expertise and self-discipline. Smartphone apps provide a new form of expertise which allows mothers to delegate mundane “administrative” tasks or to calculate specific practices, then carry them out, and in some cases, track or record these practices. I argue these changes are turning motherhood into an administrative and self-calculable activity.

*Baby Connect* [48] is an extremely comprehensive activity tracking app for mothers which includes trending charts, graphical reports, medicine and vaccine timers and notifications, weekly averages, file export capabilities and unlimited data allowances. This “data” can include information on feeding, diapers, sleeping, breastmilk pumping, temperature, games played, mood, pictures and even GPS locations (see Figure 2). This data can also be formatted and emailed as reports to spouses, nannies or doctors, or it can be used to compare with previous daily or weekly averages in order to identify trends. The app is accessible anywhere there is an internet connection, via the online account which is able to synchronise data from multiple devices.

*Baby Connect* is marketed as both a tool of convenience and as a way for working mums to feel connected and up-to-date with their children's activities, health and development, allowing “you to exchange information in real time with your spouse, babysitter, nanny or daycare wherever they are” [48]. This can even include alerts when specific behaviours or data are recorded. As noted above, the recording of data and reminder capabilities create another way for mothers who view child raising as a “project” to engage in a professionalised entrepreneurial engagement with motherhood where they can expertly keep track of their children according to data sets, and even if they are delegating particular tasks to other carers, they remain in control of what is recorded, what is concerning (alerts) and what particular activities the child engages in.

**Figure 2.** Screenshot from *Baby Connect* app indicating various facts about baby Adrien, including his age, when he last nursed, the status of his last nappy, the length of his last sleep and his mood: “Adrien is Happy”. Any of these features could be posted on Facebook or sent to other synchronised devices. Source: Seacloud Software (with permission to use image).



Writing about *Baby Connect* in *The Atlantic*, Mya Frazier claims that the app’s greatest innovation: “has been in charting and analyzing children’s data, in the process making parenthood a more quantifiable, science-based endeavour” [49] (p. 28). This is a fascinating throwback to G. Stanley Hall’s concept of “scientific” mothering. As part of Hall’s Child Study movement, mothers were encouraged to study their children, take notes on their behaviour, and compare observations with other mothers thus serving as providers of data for the experts [50]. The introduction of baby-tracking apps allows the resurfacing of “scientific” mothering where mothers are able to gather data in order to better track and understand their child’s development, and even share this with other mothers or medical staff.

The use of particular devices and techniques for collecting data, rather than relying on the “subjective” accounts or competence of the mother, privileges “objective” scientifically recorded data in the care or management of children in a time when biocitizenship is becoming increasingly implicated with new medical technologies [51,52]. In line with discussions of “cyborg-ification”—where the distinction between human and machine is increasingly blurred—I argue that apps form a digital proxy for subjective medical accounts. This suggests subjective accounts have been replaced by objective medical calculations via devices, producing a new form of calculability. This instrumentalises the body in a particular way according to a particular set of measurement devices and calculations.

In her article, Frazier interviews one mother who consistently uses *Baby Connect*, arguing that the app allows parents “to debug your baby for problems” [49] (p. 28). Again this references the



metaphor of human as machine and the concept of the cyborg. As Brown and Webster argue, this mother's management of her son via his data set is part of today's modern reflexive project:

Today, maintaining the body is a problem of technological apprehension or capture requiring the production of new systems for codification, storage, accessibility and distribution. The object of maintenance and care then is no longer simply the individual body, but representations or traces of the body in globalized systems of information and data management. [32] (pp. 80–81).

Just as Brown and Webster suggest, it is not enough to simply rely on your own (or your child's) digital data sets, it is useful to view these data sets in a specific context. Soon this will be possible as forthcoming versions of the app will enable parents to compare with other children in more detail, offering a new digitalised way of posing the question "Is my child normal"?

The dictates of the expert patient ideal suggest that patients must have expert knowledge of their health and, for mothers, this includes knowledge of their child's health and development status. It would therefore not be surprising if mothers choose to use apps like *Baby Connect* as part of their "performance" of both good mothering and the expert patient ideal. In particular, as noted above, the connection of these apps to social media allows mothers to share a digital performance of their mothering. Whether this performance could take on a competitive character remains a question for further research.

Another conceivable use for such tracking apps is their integration into childcare centres as a way of providing a digital version of a "day book" which many centres already provide for parents. This could include information on what was eaten, if there were any illnesses, complaints or concerns. The features of *Baby Connect* suggest it could support a variant of "helicopter parenting", which is defined as controlling and over-involved parenting [53,54]. In the case of apps such as *Baby Connect*, the over-involvement in children's activities could be viewed as an "off-site" version of helicopter parenting, where the "hovering" is performed digitally.

Miller and Rose argue the mobilisation of discourse does not occur through manipulation or domination, but by "forming connections between human passions, hopes, and anxieties, and very specific features of goods" [55] (p. 144). As the above discussion indicates, these hopes and aspirations influence concerns over childhood health and development leading to the creation of apps like *Baby Connect*. In addition, a new category of toys, games and software has recently emerged which focuses on infant development, targeting aspiring middle-class parents. The discourse of "infant brain science" has meant that gendered toys are often rejected in favour of "educational toys" fostering imagination, creativity, social skills and education [56]. Infant brain science focuses on the critical learning period of infant to three years of age [57]. Apps like *Baby Connect* can act to reassure parents that their children are being adequately stimulated whilst in the care of others. In addition, there are apps that focus specifically on intellectual stimulation for infants, drawing on the discourse of Infant Brain Science, such as *Baby Guide First Year* [58] and the *Baby Brain Development Guide* [59] which are both temporally tailored towards a normative framework of developmental cues and expectations. These apps could ease parental anxiety over their inability to supply constant intellectual stimulation as they provide games, visual items and tasks, but their

temporally tailored format could in turn raise concerns over speed of development if a child were to fall behind the “normal” timeframes. These apps and the discourse of “infant brain science” encourage a specifically classed version of “professionalised mothering” aimed at increasing childhood intelligence and accomplishment according to neuroscientific principles [39].

## 10. Ebluebook

The Australian state of New South Wales’s (NSW) Ministry of Health have digitalised the “Blue Book” which is a folder of information that mothers are given during pregnancy in order to record information about their prenatal visits, the health of the baby in utero and the development and health of the baby postnatally. This *ebluebook* app is personalised and temporally tailored and includes a version of *Save the Date* (another NSW Ministry of Health app) with reminders for immunisations, health checks, growth charts and information on development.

The app claims to give parents easy and convenient access to their child’s health records no matter where they are. The deployment of discourses of convenience and mobility produces new expectations that parents regularly update the book and, as “mobile” subjects, always be able to monitor and access their child’s health history. Because child health is “put back in the hands of the consumer” [60] (pp. 5–6) convenience and mobility are tied to empowerment, but also to responsibility. The app serves to responsabilise parents for their children’s health monitoring and developmental requirements and if parents do choose to share the *ebluebook* data with their health care provider it allows that provider to discipline parents who have missed developmental health checks such as immunisations. Therefore this device can work as a tool for surveillance and discipline as well as convenience.

The *ebluebook* app also encourages parents as consumer-citizens to develop specific scientific and medical understandings of their children’s growth and development, what Rose and Novas [29] would term “informational citizenship”. This biomedical literacy encourages particular behaviours and monitoring such as the regular measuring of height and weight in order to compare to norms or averages, and promotes alignment with government regulations for immunisations. These outcomes align in order to emphasise the dual role of the mother as both a good citizen and an expert proxy patient for her child/children.

Brown and Webster argue that electronic patient records maintain the body “both as an individual physical entity and as an abstract informational artefact” [32] (p. 81). Therefore the *ebluebook* could be seen as a new mobilisation of the body, another digital artifact just like the digitalised identity of the foetus and child on social media [52]. The implication of a digital identity means we now also measure ourselves (and our intimate others) according to digitalised health data and our social media presence, which also creates a measurable version of our “likeability”.

## 11. Pregnancy Apps for Men?

There are far fewer apps related to pregnancy (and parenting) for men than for women and it is important to note that these apps are marketed in a very similar way to pregnancy books for men, focusing on humour and tidbitisation of information [61,62]. They also tend to be significantly

gender stereotyped and somewhat patronising. For example, *mPregnancy—for men with pregnant women* includes:

great illustrations of how the baby develops and describes the size in terms that men understand e.g., similar to the size of a football, or a bottle of beer [63].

The app appeals to traditionally masculine-gendered activities such as providing information on how to prepare a nursery, and dealing with finances and insurance. There are no pregnancy apps on the market (that I have found) that provide this kind of information for women, even though many women would undertake these tasks regardless of whether or not they have a male partner and could find the inclusion of such information quite useful.

The app *Pregnant Dad* shares some features with *mPregnancy* including being marketed humorously as an app for “surviving pregnancy as a father-to-be” [64]. *New Dad—Pregnancy for Dads* app also appeals in this way with: “insightful and humorous descriptions” [65]. Just like many pregnancy texts for men, pregnancy apps deploy humour in an attempt to tone down the serious nature of the information, whilst also simplifying it; men are seen as the “bumbling assistants” [62]. In contrast, guidebooks and apps for women are often directly marketed as serious expert guides for the responsabilised expectant woman, albeit with the odd exception [66]. The *Pregnant Dad* app again specifies the digestibility of information: “Sliced in 2–3 bits per week it has the right amount of information for us men to follow” [64] and another, *New Dad* emphasises this tidbitisation of information: “Surprise your wife with tidbits of information about the development of your baby” [65].

The *New Dad* app also focuses on the woman’s experience, emphasising the importance of keeping her “comfortable and happy” and even includes a “‘keep your wife happy’ widget” [65]. These kinds of inclusions remind us of the traditional man/woman split of rationality *versus* emotionality. Men, who are more rational, need to be given information on how to keep their emotional wives happy! The features of these apps for men suggest a particular role for men during pregnancy, one which is “backgrounded”, as Sunderland argues in relation to parenting magazines [62,67]. A male partner’s role in pregnancy and parenting is still discussed, or in the case of apps “designed”, in a somewhat condescending or patronising manner. Men are constructed as being barely capable of their “supporting role” and need all the help they can muster, including humorous, simplified tidbits of information, and reminders about what being a good partner (and good dad) involves. Together, these features render fathering an issue of “keeping up appearances” for the female partner, rather than any serious attempt at engaging in the careful work of parenting. This is merely “surface” work which suggests what men are supposed to be doing (impressing mum) and prompts them, with the aid of a push notification, to do exactly that!

These features are reminiscent of the nature of many support resources for men with pregnant partners, suggesting that although parenting and fathering appear to be “changing” in terms of policy and sociocultural practices and expectations (including more involved dads and more dads as primary carers), the mechanisms and devices to support these changes, such as apps, are lagging behind. In their book “Constructing Fatherhood”, Lupton & Barclay argue that whilst women are

encouraged to seek advice and information on pregnancy and mothering, these continue to be seen as essential components of femininity:

not as split from womanhood as fatherhood may sometimes be split from manhood. Men and women, therefore, are negotiating parenting arrangements in a context in which it is still considered that the mother is more important to her child's welfare than the father and "instinctively" possesses a greater capacity for nurturance [61] (p. 147).

This perspective is noticeable in the ways in which these apps for men target specific masculinised behaviours (such as preparing a nursery and dealing with finances) separately from parenting behaviours, and also play on the belief that men have no innate knowledge or intuition when it comes to being a parent and nurturing a child. As this article has demonstrated, apps marketed for maternal subjects are designed instead, to target responsabilisation or what I call "being-for-intimate-others".

## 12. Conclusions

A range of research has considered the collection of resources drawn upon during the transition to motherhood, which include self-help books, magazines, friends and relatives and the internet. Smartphones and apps, along with other forms of digital health technology, must now be incorporated with these other resources and are deserving of further research. As this article suggests, smartphone apps and social media sites may represent a particular way for women to engage with the neoliberal project of responsabilisation. The health-conscious pregnant or maternal subject is now likely to view apps and social media sites as a means to improve and monitor their pregnancies, health and their children's development and health. From this perspective, apps in particular are claimed to be empowering technologies which enable women to take control of their experiences and whilst doing so, this enables them to more efficiently enact the expert patient role. This in turn works as a display of competence as a good mother, or mother-to-be. These apps also work to represent the unborn as already a baby (or child) which has implications for pregnant women. These women are not simply acting for the self but also for the unborn "other", referred herein as "being-for-intimate-others".

I argue that devices such as apps and social media platforms that discuss pregnancy and parenting may be appealing because, when mothering is so intensive (as Hays [17] suggests), these technologies allow for the possibility of delegating responsibility for certain calculations, reminders and tasks. This supposedly makes mothering easier because there is no need to remind oneself if it is possible to rely on the push notification or "push responsabilisation" as I have characterised it. But this pushiness is not necessarily always convenient and rather than being a pleasant reminder, could develop into a rude intrusion. Nevertheless these devices are becoming more common and certainly offer us a way to conceptualise different ways of pulling back from intensive mothering in order to be a more "relaxed" mother. Some apps and social media platforms also allow women to share experiences with each other which can be supportive and comforting.

Apps are representative of something uniquely distinctive about the way we order, engage with and reshape our bodies and biology today. They are reflective of a wider set of cultural and social

changes in the understanding of our identity, our “lifestyle” and our body. Apps format motherhood and pregnancy in a new way, instituting new rules into new devices and offering templates which actively shape meanings and practices. Apps also represent a “tidbitisation” of information which is delivered directly into the user’s intimate sphere, no matter where they are. This “device-ification” of mothering purports to turn it into an administrative and calculable activity, valuing data over subjective experiences and changing the meaning of what it is to mother and be a mother. Apps and social media platforms that facilitate the portrayal of the unborn and the sharing of pregnancy and parenting experiences are also representative of the contemporary intersection between social media, medical advice, expectations of self-management and notions of convenience. They create new social relations and valuing practices, such as “likeability” on Facebook, which have the potential to alter our understandings of health and identity.

Future research should consider the multiplicity of women’s engagement with these apps across the transition to first-time motherhood and for parents attempting to manage child health. It would also be useful to conduct more research on the possible inconvenience of apps. Clearly the “pushiness” of push responsabilisation would not always be convenient and could develop as an intrusion into people’s daily routines. It would be productive to direct focus onto the lived experiences associated with apps rather than lauding or criticising the content of apps. Further questions to consider in an empirical study include: Who adopts these apps and why? Who rejects these apps and why? Are push notifications ignored, considered obtrusive or do they prompt specific practices or actions? How are apps and social media sites used by pregnant women and first-time parents? How do apps and social media sites maintain, reproduce or challenge pre-existing gender inequalities in parenting?

### **Acknowledgments**

I am grateful to my supervisor, Kane Race, whose advice on this area of my research was always insightful and productive.

### **Conflicts of Interest**

The author declares no conflict of interest.

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# Detecting the Visible: The Discursive Construction of Health Threats in a Syndromic Surveillance System Design

**Baki Cakici and Pedro Sanches**

**Abstract:** Information and communication technologies are not value-neutral tools that reflect reality; they privilege some forms of action, and they limit others. We analyze reports describing the design, development, testing and evaluation of a European Commission co-funded syndromic surveillance project called SIDARTHa (System for Information on Detection and Analysis of Risks and Threats to Health). We show that the reports construct the concept of a health threat as a sudden, unexpected event with the potential to cause severe harm and one that requires a public health response aided by surveillance. Based on our analysis, we state that when creating surveillance technologies, design choices have consequences for what can be seen and for what remains invisible. Finally, we argue that syndromic surveillance discourse privileges expertise in developing, maintaining and using software within public health practice, and it prioritizes standardized and transportable knowledge over local and context-dependent knowledge. We conclude that syndromic surveillance contributes to a shift in broader public health practice, with consequences for fairness if design choices and prioritizations remain invisible and unchallenged.

Reprinted from *Societies*. Cite as: Cakici, B.; Sanches, P. Detecting the Visible: The Discursive Construction of Health Threats in a Syndromic Surveillance System Design. *Societies* **2014**, *4*, 399–413.

## 1. Introduction

The term syndromic surveillance describes a collection of methods within the field of public health surveillance. These are characterized by their use of secondary sources, referring to data collected for a variety of purposes only indirectly related to population health. For example, over-the-counter medicine sales, or records of ambulance dispatches from a hospital, or records of emergency room visits can be considered secondary sources, because these data are not collected with the primary intent to perform public health surveillance. Using this formulation, syndromic surveillance is often positioned as an efficient use of already collected data [1].

International public health institutions rely increasingly on automated and globalized surveillance, and this shift follows a rationale of vigilance and preparedness where “marginal and dangerous” [2] events are given priority over broader determinants of health [3]. Within the discourse of syndromic surveillance, numerical representations of populations and the application of statistical analyses are essential to the task of constructing meaning from diverse sources of surveillance data. The use of these types of surveillance methods follows a long tradition of health discourses where individuals and populations are constructed as knowable and governable by establishing comparative systems to analyze their similarities and differences [4] (p. 190).

Equally important is the idea of disease as a collection of symptoms and signs observed by a medical gaze [5] (pp. 88–106). The idea of extending the medical gaze and the multiplication of ways of representing individuals and populations are not exclusive to public health institutions. Two other analyses included in this special issue also deal with systems of classification and comparison, which make use of similar discourses. In the two studies, these systems have consequences for how motherhood is performed [6] and how people reflect about themselves [7].

We analyze reports describing the design, development, testing and evaluation of a European Commission co-funded syndromic surveillance project called SIDARTHa (System for Information on Detection and Analysis of Risks and Threats to Health). We start with the assumption that information and communication technologies (ICTs) are never value-neutral. They necessarily reflect the viewpoints of their designers, the influence of others involved in their construction and the consequences of the material limitations encountered during their development [8–10]. With our analysis, we aim to identify how a syndromic surveillance discourse privileges or excludes specific types of knowledge and practices. We show that the discourse of syndromic surveillance constructs the health threat concept as a sudden, unexpected event with the potential to cause severe harm and one that requires a public health response aided by surveillance. Based on our analysis, we state that when creating surveillance technologies, design choices have consequences for what can be seen and for what remains invisible. Finally, we argue that syndromic surveillance discourse privileges expertise in developing, maintaining and using software within public health practice, and it prioritizes standardized and transportable knowledge over local and context-dependent knowledge. We conclude that syndromic surveillance contributes to a shift in broader public health practice, with consequences for fairness if design choices and prioritizations remain invisible and unchallenged.

## 2. Background

The earlier applications of syndromic surveillance were characterized by the use of health-related data that preceded diagnosis and the continual monitoring of disease indicators to detect outbreaks of communicable diseases earlier than traditional methods [11–13]. More recently, the definition of syndromic surveillance has broadened to include the monitoring of non-communicable diseases and other health conditions, such as heat-related illnesses, injuries caused by tornadoes or respiratory illness after wildfires [14].

A well-known example of syndromic surveillance is Google Flu Trends [15,16], which uses search queries entered by users into Google as indicators of influenza outbreaks. The developers of the system have claimed that they can “accurately estimate the current level of weekly influenza activity in each region of the United States” [15] (p. 1012), although the estimates have not always been accurate [17,18]. While the system itself is well-known, it is highly unusual, as it is run by a private company. The majority of syndromic surveillance systems are used by public institutions, such as regional and national health authorities.

Many different types of ICTs are used for communicable disease surveillance. Bravata *et al.* [19] provide a broad review of 115 systems and identify those that provide syndromic signals. Other reviews focus on syndromic surveillance and include more recent systems [20,21]. Additionally,

the Triple-S project provides an extensive list of syndromic surveillance systems used within Europe [22].

### 2.1. Challenges

The impact of syndromic surveillance on the already limited resources available for public health, for example the costs of dealing with potentially large numbers of false positives generated by these systems, has been discussed by public health practitioners and scholars. One of the earliest challenges was by Reingold [23] who asked: “If syndromic surveillance is the answer, what is the question?” Reingold points to the scarce resources within the field of public health and challenges those who call for the further development of syndromic surveillance to detail not how detection could be improved, but if public health response would be improved in any way if these systems are implemented. He emphasizes the importance of building capacity within the public health departments instead of collecting and analyzing data externally, an activity often performed by for-profit corporations in departments without academic partners. In a discussion on the difficulties of creating a nation-wide syndromic surveillance, Mostashari voices concerns about the relationship between detection and response capacity:

We have 80 percent of the nation covered but we really have nothing covered, because signals come and go, and an e-mail maybe is sent out, and there’s no local capacity . . . If you’re doing analysis for a thousand different towns, villages, cities, whatever, every day you’re going to find alarms. ([24]; cited in [25])

Similarly, Heffernan *et al.* [26] state that although their syndromic surveillance systems have been beneficial in detection, they are “essentially ‘smoke detectors’ and call for prompt investigation and response if they are to provide early warning of outbreaks” [26]. They continue to recommend that efforts for bioterrorism preparation should focus on hiring well-trained public health professionals with responsibilities that are broader than just bioterrorism.

Fearnley [25] analyzes the debates surrounding the development and use of several nation-wide syndromic surveillance systems in the U.S. and identifies a central conflict: the early syndromic surveillance systems were designed primarily for national bioterrorism preparedness, but the data collection and reporting were assigned to public health institutions tasked with maximizing the health of human populations. These systems collected data from many different, non-traditional sources and transferred them to health departments. However, the collected data were not immediately helpful, because “[m]ore information means more interpretive work, without certain benefits; and more detected events requires more epidemiological responses, without (at this point) the necessary epidemiological resources to undertake them” [27] (p. 84). Fearnley points out that without the resources to interpret the incoming data, the newly developed systems were not helpful to epidemiologists.

In syndromic surveillance systems, collecting data is the key to tackling public health problems. All syndromic surveillance systems are constructed with the assumption that gathering more data

helps public health authorities make decisions. Analyzing the practices that accompany ICT-based surveillance systems in public health, French [28] identifies the assumption that more data are helpful as a consequence of an immaterial conception of information:

[. . . A]n immaterial conception of information, whether implicit or explicit, assumes that information signifies in the same way regardless of time or place. As a consequence of this assumption the significance of information-processing practices is minimized; the material diversity of such practices, and the effort required to unify them, is underestimated. French [28] (p. 111).

As French argues, data collection also comes at a cost. It requires significant amounts of work to standardize data, to connect systems and to ensure that data are transferred correctly from one place to another. Ignoring the cost of collection or, more broadly, the material dimensions of information, causes problems for ICTs. The very immediate consequence is that it requires more work. This is the work of maintaining and interpreting.

In their extensive study of classification, Bowker and Star point out that data entry is never a trivial task: it requires trained staff to perform; it is prone to mistakes with respect to the classifications being used, and there are always cultural variations in what is interpreted as worthy of recording and what is omitted [29] (p. 107). Additionally, they state that there is always a tension between the standardization of lists centrally, and their use locally [29] (p. 139). Finally, they emphasize that “all category systems are moral and political entities” [29] (p. 324). As syndromic surveillance systems rely heavily on rigid classification schemes, they exhibit these characteristics.

Based on a study of medical records, Berg and Bowker also argue that data collection and recording methods influence how work is organized and which practices are considered to be part of that work [30] (p. 532). Similarly, emphasizing data collection and information generation in public health surveillance modifies the definition of activities that belong to public health, and some types of expertise are prioritized over others. For example, when syndromic surveillance is used, familiarity with developing and maintaining software becomes an important requirement for public health practice.

The concept of immutable mobiles, introduced by Latour [31] (p. 227), provides a way to engage the processes of informatization and standardization in syndromic surveillance. Latour uses the term to refer to objects that are archivable and comparable regardless of their age, place of origin and context of use. For example, an entry in a table listing the admissions to the emergency room can be considered an immutable mobile, because, unlike the locally bound emergency room, it can be transported easily, compared to other descriptions, or even be organized in charts and statistics to construct an aggregated view of events that occur in emergency rooms. The complexity of the emergency room, or any other phenomenon, is overcome by translating it into intelligible and stable objects. The power of these objects is tied to their simplicity, which makes complex phenomena observable and manageable from a bird’s-eye view. For this reason, immutable mobiles allow power—the power to see and the power to manage—to be exerted, irrespective of time and place.

However, the work of keeping these objects stable is often unaccounted for. In fact, the structures that maintain them, such as the layout of the rows and columns in a table or the procedure for filling

out the details of each entry, like the objects, must also remain constant across places and contexts for them to remain immutable. The concept of immutable mobile is descriptive, allowing us to identify and describe certain objects in our analysis. We focus on how they are created and how they are maintained. We then take a step further by problematizing the aspects of their creation and maintenance. The immutability of these objects can only be accomplished by mobilizing people and material resources around them and by keeping these networks together through constant work [31]. For example, the output of the peripheral surveillance systems are brought closer to each other by categorizing syndromes, collecting data and creating graphs, but constant work is required to uphold the categorizations. Given the costs and risks of immaterial conceptions of information [28] and the work of standardization, we ask the question of who benefits or what there is to be gained.

### 3. Analysis

SIDARTHa is designed to be installed at health institutions to monitor sources of emergency data, including records of emergency dispatches and reports from emergency practitioners. We chose to analyze the SIDARTHa project, as it is one of the largest syndromic surveillance systems developed in Europe, and it involves multiple partners from different member states. Similar projects that focus on single health institutions separately instead of one centralized system have also been developed in the U.S., such as RODS (Real-Time Outbreak and Disease Surveillance) [32]. Although the majority of syndromic surveillance systems in the last decade have been developed and used in the U.S., we consider ourselves more qualified to analyze a European project due to our previous experience in public health surveillance in an EU member state [33].

Our analysis is based primarily on the seven project reports published by the SIDARTHa project between the years 2009 and 2010. They describe the process of design, development, testing and evaluation of the SIDARTHa syndromic surveillance system. These reports form a suitable corpus for discourse analysis, because the authors describe different stages of the project in detail, and they state their reasons for their decisions. The earliest reports focus on literature reviews and pre-studies; later reports describe the design and development of the system, and the most recent ones discuss testing and evaluation. This progression allows us to observe changes and shifts in the project and see how different ideas evolve throughout the design and development of the system.

We began our analysis by reading the seven project reports and marking all sentences that make knowledge or truth claims related to the overall argument, that state a hypotheses or that present research questions. We continued by marking sentences that inform the reader about the existence of entities outside of the text. In this category, we included any statements that refer to uncertainty, because such statements also provide insight into what is considered to exist only partially outside the text. We also marked all sentences that refer to individuals or groups of people, because these statements show how the text constitutes subject positions that are relevant to its own argument. After this process was completed, we read only the marked sentences for each report and tried to group them according to common themes based on either the topics they discuss or the frequency of the words they use. We examined these themes in relation to knowledge [34] (p. 14), truth [35] (pp. 92–96), [36] (p. 12) and subject positions [36] (p. 15). We repeatedly asked the question “what

is considered true in this statement?” and wrote down our interpretations, while keeping in mind the identified themes for each report, the collection of marked sentences, as well as the unmarked sentences referenced by the marked ones.

### 3.1. *What is a Health Threat?*

In the SIDARTHa reports, the aim of the project is stated as detecting public health threats [37] (p. 1). The reports further describe their goal as helping public health authorities to become aware of health threats earlier or even to prevent them. The scope of the term health threat within the project reports is very broad: it refers to diseases, both communicable and non-communicable [37] (p. 1), but it also refers to other events, such as floods, heat waves and even volcanic eruptions [38]. Additionally, it can refer to acts of bioterrorism, which most commonly refer to the intentional release of biological agents, such as anthrax, into the air in large quantities with the intent to harm others [37] (p. 7).

From the perspective of syndromic surveillance systems, health threats first become visible when other surveillance systems capture their traces. For example, a person experiencing high fever and a sore throat may visit the emergency room, where her visit is recorded in the admission logs, or several people living in the same district might post on social media platforms about suffering from shortness of breath and digestive problems. In both cases, the experiences of these individuals are recorded, and those records are then accessed by syndromic surveillance systems. For these systems, the health threat is best defined in terms of data and signals: “Early detection of public health threats in general relies on the components: timely and reliable data; the sensitivity, specificity; and timeliness of signals detected.” [39] (p. 3).

Syndromic surveillance relies on the presence and the functioning of other surveillance systems. For example, the primary motivation for tracking ambulance dispatches is not to generate signals for syndromic surveillance. Ambulances are dispatched to retrieve patients, and the signals are used for a variety of purposes. Ambulance drivers may need to track their working hours, or hospital administrators may need to know how many ambulances are available to respond in case of emergencies, *etc.* Every departure and arrival of the ambulance is logged for a multitude of reasons, and syndromic surveillance systems depend on these logs, but the logs themselves are not produced specifically, or at least not primarily, to support the practice of syndromic surveillance.

The SIDARTHa reports describe a system that can be used to collect emergency data in different health institutions in multiple European countries independent of one another, each with their own rules and regulations for gathering data. To form a more homogeneous set of records, the designers propose a coding standard to convert the local data to the SIDARTHa-compatible version. Organizationally, the data remains locally stored, as one of the aims of the system is to ensure that the collected data does not leave the collecting institution or regional authority.

The standardized data format is a string of numbers with different fields. The designers state that “[t]he minimum data set for syndromic surveillance must contain enough information to produce the number of cases per day for temporal syndromic surveillance” [40] (p. 6). It includes seven variables: the anonymous case identifying number, date, geographic reference, syndrome, age,

gender and severity. The final three variables are called modifiers, because these are not essential to constructing the number of cases, but the information contained within them may be relevant for certain syndromes, such as gastroenteritis (or stomach flu) in children or heat-related illness in the elderly. These particular variables are chosen based on a survey of availability within the countries that participate in the SIDARTHa project, and it is the minimal set of properties that all of the participants are able to provide.

Using the standard, it is possible to represent each field using numbers, even when receiving data from different sources. For example, the case identification can be filled using the call identification code if the data are provided by an emergency medical dispatch center, or it can be filled using the patient identification code if the provider is an emergency department. The date is converted to a series of unambiguous numbers by specifying the order that day, month and year appear in the string. Geographic reference is more heterogeneous; the numbers contained in this field can refer to X and Y coordinates generated using the Global Positioning System (GPS), health zone codes, post codes or community codes. Attempting to fit gender into this form brings the ubiquitous problem of coding gender as a binary and the transition from sex to gender in the system vocabulary. The original specification of the standard provides “0” for male and “1” for female, and the final implementation of the system changes the order and adds a third category, “unknown” [41] (p. 33).

All of the variables we have described above pertain to the identification of persons and their locations. The actual work of describing syndromes occurs in the remaining two variables: syndrome and severity. The syndrome category requires the largest amount of work to convert into a number. Syndromes are divided into six categories: influenza-like, gastrointestinal, respiratory, intoxication, environment-related (heat-related) and unspecific. Since the system is designed to be compatible with many different sites, a multitude of conversion tables are provided to make possible the homogeneous coding of cases for any SIDARTHa system. The coding manual provides a series of tables to allow this conversion, where the codes of other, more established standards, such as the International Classification of Diseases (ICD), can be converted to the SIDARTHa standard [40].

At the end of this conversion, the health threat is narrowed from a wide variety of uncontrollable events to a series of numbers that can be transmitted without change and one that refers to the same thing regardless of context. Unlike the data collected in each institution, which carry marks of local practices particular to each case, the resulting string is constructed to function independently of its context. It is easily comparable and combinable across different databases. In Latour’s terms, this standardization creates an immutable mobile [31] that can be used for statistical analysis in any institution. Freed from their earlier contexts, these strings of numbers gain a comparability that the contextually-rich data available at the institutions do not possess. Once they are created by the SIDARTHa software, their comparability is put to use through the work of different classification and detection algorithms.

The classification may indicate change over time, or it may include a spatial component that connects the data points to particular places using GPS coordinates or postal codes. Although the algorithms vary depending on the input and the intent, the primary purpose of this analysis is to divide the data points into two groups: expected and unexpected. The data points that end up in the expected



category are not of high importance to the system designers. These may indicate low-risk diseases in low volumes or a seasonal variation in an illness (implying that the change occurs every year). The designers of SIDARTHa are much more interested in the unexpected category. This category includes all of the data points that have been marked by the system as deviating from the norm. These unexpected events are all potential health threats within the system.

The designers state that one of SIDARTHa's strengths is its flexibility: "[T]he SIDARTHa system can easily be adjusted to cover additional health threats, in this case the volcanic ash cloud with new syndromes such as traffic accidents and cardiovascular syndrome." [42] (p. 10). This flexibility is not only due to the way the system has been constructed, but also because of how the discourse of syndromic surveillance describes health threats. In another report, they point out that "[o]ne important feature of syndromic surveillance is flexibility, which allows the generation and monitoring of syndromes according to suddenly emerging, potential health threats" [39] (p. 3). In this definition, a health threat is a sudden event that has the potential to affect population health. The words "suddenly" and "potential" highlight the issue of the absent subject in the definition: for whom is the event sudden or unexpected, and what is meant by the potential to affect? The concern about sudden events can be viewed from the perspective of public health authorities who would be expected to respond to an event. Suddenness can then be stated relative to how long it would take for the authorities to act (by contacting the patients, by visiting the clinics, by issuing public notices, *etc.*) when the health threat appears. Defining the limits of the word "potential" are much more difficult. For example, an influenza outbreak can sometimes spread rapidly in a population, but result in only minor suffering as the infected experience the discomfort of a sore throat. However, it can also cause major illness in those who are infected and even become life-threatening for those who already suffer from other conditions. Complicating the decision even further, the difference between the two is often not clear until its effects are experienced by individuals. The public health response is required to negotiate this conflict and to come to a decision about the limits of the potential of a disease to affect the population.

In the SIDARTHa reports, a particularly unusual event serves to illustrate the potential usefulness of the system for public health response, even in cases of non-detection. Following the eruption of the Eyjafjallajökull volcano in Iceland in 2010, the project consortium developed a method to evaluate the potential public health impact of the ensuing ash cloud. The event is described as offering a suitable scenario for testing the system, although the authors also point out:

This report uses the term 'volcanic ash cloud' without determining if the ash cloud was a cloud or rather a contamination. Therefore, it should be understood that the term 'ash cloud' used throughout this report is not to be understood as a scientific term. It should be further noted that the authors do not intend to give any prejudice on the question if there was any risk to health at all caused by the ash cloud as such. The intention of this rapid assessment was to test the capability of the SIDARTHa concept and pilot syndromic surveillance system to be timely adjusted for monitoring a suddenly occurring event potentially affecting health [emphasis in the original] [38] (p. 3).

A sudden event and its potential to affect health both appear in this justification for performing the ash cloud assessment using the SIDARTHa system. Establishing an event as a health threat occurs before the investigation begins, but the results of the investigation do not fully resolve the status of the event either. In the four SIDARTHa implementation sites in Austria, Denmark, Germany and Spain, the system identifies no significant correlation between the volcanic ash cloud and the unusual signals of respiratory conditions reported during the same period. The authors state that “further in-depth analysis of case characteristics is necessary” [38] (p. 16), but also mention that their investigation, and the fact that it was possible to perform it at all, demonstrates the “flexibility of syndromic surveillance systems to be used for ad-hoc surveillance after suddenly occurring events” [38] (p. 16). In the booklet *Generic Public Health Preparedness in Europe*, a brief description of the SIDARTHa project is accompanied by several quotes from Dr Thomas Krafft, the scientific-technical coordinator of the project. Commenting on the volcano investigation, he states:

The European Centre for Disease Prevention and Control asked us to test out SIDARTHa during this time to see if there were any health impacts from the volcanic ash plume . . . . We found no increased demand for emergency care services. It is important to be able to distinguish between ‘real threats’ and ‘perceived threats’ [43].

This division between real and perceived threats positions SIDARTHa, and by extension, syndromic surveillance, as the arbiter of truth for public health practice in the implementation sites. The operations of SIDARTHa are also perceptions, although they are perceptions of expertise, supported by advanced ICTs and public health authorities. The “real” in the quote can be interpreted as describing events that public health authorities should act upon to improve the health of a population; the “perceived” can also be interpreted as events that they should act upon to reassure the population that there is no health effect. In either case, the detection possibilities offered by SIDARTHa are geared towards shaping the type of public health response following an event.

In the beginning, the traces of different individuals are collected in various public health surveillance systems and converted into the SIDARTHa standard to create a more uniform unit that is compatible with the different methods of statistical analysis. Up until this point, the traces of individuals shed their context until only the bare minimum remained. The contents of that bare minimum are defined by the SIDARTHa standard. After reaching that point, the work of inscribing a new context into the numbers begins. The first step is the statistical analysis, which constructs the objects that public health institutions can act on, followed by the visualization of the results, which show the traces in the unexpected category. The process that begins with the set of recorded traces and eventually becomes the evidence for the existence or the non-existence of the health threat depends on a long chain of translations between different systems and different mediums. When the authors assert their claim as “[e]mergency care demand shows a pattern allowing for detection of unusual aberrations from the expected demand” [44] (p. 20), they refer to the large web of surveillance systems that individually construct and link the patterns, detections, aberrations and expectations.

### 3.2. Design Choices and Expertise

The SIDARTHa system uses emergency care data to monitor health threats. The project researchers divide it into four data sources: emergency medical service (EMS), emergency medical dispatch (EMD), emergency physician service (EP) and emergency department (ED) data. Each source has different properties that make it more or less suitable for inclusion in a syndromic surveillance system. For example, the authors note that ED data are often collected electronically, while EMS data are filled in paper forms that are then transferred to the computer, making the latter more difficult to connect to an ICT-based surveillance system [37] (p. 20). The authors also mention that emergency data covers only severe cases, because patients with mild symptoms are not very likely to call the emergency medical service or to visit an emergency department [37] (p. 22). At the same time, emergency departments receive patients and respond to calls outside the working hours of other health services [37] (p. 22).

The decision to use emergency data for syndromic surveillance has consequences for the types of events that can be detected and for those likely to remain invisible. In this case, one consequence is being able to detect severe cases and not being able to detect mild ones. For example, the authors state that “since gastrointestinal problems do not mainly lead to the need of emergency medical care treatments, these outbreaks can only be identified by a syndromic surveillance system if the outbreak occurs under special circumstances (*i.e.*, symptoms in a group from abroad)” [42] (p. 15). The system itself makes events that manifest with acute symptoms more visible. This is in line with the vision of syndromic surveillance as a tool of preparedness for sudden, unexpected and highly dangerous events. By beginning with the aim of detecting health threats and then setting up a system that is suited to the detection of severe illness rather than mild illness, the designers contribute to the definition of a health threat. In the previous examples, the health threat was a sudden event with the potential to affect health, whereas now a health threat is specified further as an event that can cause severe illness with sharp and sudden symptoms.

During the development of the SIDARTHa system, the ICT company, BeValley, programmed the system to match the specifications of the designers. In the evaluation report, the authors state that “BeValley agreed to adjust and update the system in the future, but the question remains how this can be sustained also with additional funding” [42] (p. 10). They also ask: “If the regional system cannot easily be repaired by the future users, how does that affect the usefulness and acceptance of the system?” [42] (p. 11). The authors anticipate that future users in emergency care institutions will have ICT staff who can install the software and program the data transfer [42] (p. 11), but they do not elaborate on either whether emergency care institutions do in fact have such capacity or if that capacity should be found within emergency care. The expertise required to perform public health surveillance grows when SIDARTHa or a similar syndromic surveillance system is introduced, and that new practice privileges ICT expertise more than before.

Finally, the work of classifying and sorting does not end with the programming and installation of the system. During the data analysis study, Rosenkötter *et al.* [39] report numerous errors that need to be resolved locally by the practitioners attempting to perform analyses based on emergency

data. For example, the authors find that it is not possible to analyze unspecific syndromes using the Austrian emergency physician service data due to repeated entries for the same incident, while using the emergency department data, the only option is to analyze unspecific syndromes, because the source does not list the reasons for care. The Belgium emergency physician service data arrive with delay, causing difficulties in developing a syndrome-specific coding, and the emergency department data is not possible to analyze fully, because the systems recording the data have changed recently. The authors also describe the necessity of taking into account ICD shortlists used by physicians at different sites. These lists lump the detailed categories of the ICD into larger groups, allowing the physicians to quickly assign codes without referring to the extensive ICD documentation every time. However, the mappings of these shortlists differ from site to site, and they do not combine easily when centralizing the data. It is not possible to ignore the shortlists either, because similar cases may be assigned to different syndromes if the mappings in the shortlists are not taken into consideration. Although these events may sound like exceptions to the rule of smooth classification, as Bowker and Star [29] point out, the work of classification always includes these complexities and tensions.

#### 4. Conclusions

We have demonstrated how a discourse of syndromic surveillance constructed the health threat concept as a sudden, unexpected event with the potential to cause severe harm and one that requires a public health response. Based on our analysis of reports from the SIDARTHa project, we stated that when creating surveillance technologies, design choices have consequences for what can be seen and for what remains invisible. We argued further that syndromic surveillance discourse privileges expertise in developing, maintaining and using software within public health practice, and it prioritizes standardized and transportable knowledge over local and context-dependent knowledge.

ICTs are not value-neutral tools; they privilege some forms of action, and they limit others. They are imbued with values, and different people benefit or suffer from their use differently. Latour's definition of technology as "society made durable" [45] underlines the potential of ICTs to stabilize existing social processes. Leaving design decisions unexamined can perpetuate current epidemiological classifications, which may already be problematic [46]. Furthermore, Fearnley states that "[s]yndromic surveillance itself, with its orientation towards unexpected events and nonspecific objects, inevitably moves epidemiology in new directions." [27] (p. 84). French's analysis of ICT use within public health defines some of these new directions:

[...A]n over-arching immaterial conception of information imbues some kinds of information with more import, for surveillance, than other kinds of information. Specifically, this conception encourages the collection of abstract, digitized signifiers, while simultaneously marginalizing other kinds of embodied, contextual information. Indeed, the pursuit of immaterial information for public health surveillance produces a dominant but superficial epidemiology at the expense of other potentially more effective epidemiologies. [28] (p. 6)

Syndromic surveillance systems are not costless solutions, because gathering information and sustaining surveillance require work. They also require a different kind of expertise not always found in public health institutions. Moreover, syndromic surveillance relies on a particular definition of health threat, which focuses on catastrophes and rare events. The practice of syndromic surveillance contributes to a shift in broader public health practice, and although this is not problematic in itself, since practices can always change, the question remains: what does syndromic surveillance mean for fairness? If it orients public health towards the detection of catastrophes or sudden events with severe consequences, what happens to other types of events that do not produce such signals? For example, to what extent can syndromic surveillance deal with chronic illness or aid those who suffer from health issues due to poverty? Public health practice is a large field, and there may be a place for different surveillance systems that monitor different types of illness. However, discussions of syndromic surveillance should not stop at sensitivity, specificity and timeliness, but also address questions of fairness.

### Author Contributions

Baki Cakici collected the textual material. The authors performed the analysis and drafted the manuscript together. Both authors read and approved the final manuscript.

### Conflicts of Interest

The authors declare no conflict of interest.

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# Managers' Identification with and Adoption of Telehealthcare

Jane Hendy, Theopisti Chrysanthaki and James Barlow

**Abstract:** This paper presents managerial attempts at implementing telehealthcare. Our longitudinal, ethnographic case studies document both successful and failed implementations across five health and social care organisations in England. We draw on theories of organisational identity, sensemaking and sensegiving to highlight how managerial organisational identities can inhibit the uptake of digital health technologies. Managers who strongly identified with their current role at work felt threatened by the intended change; a telehealthcare mode of care delivery. When a strongly identified workforce agrees with this assessment, managerial and employee sensemaking and sensegiving coalesce, forming a united front of resistance that prevents further adoption of the innovation.

Reprinted from *Societies*. Cite as: Hendy, J.; Chrysanthaki, T.; Barlow, J. Managers' Identification with and Adoption of Telehealthcare. *Societies* **2014**, *4*, 4286445.

## 1. Introduction

A key agenda for governments worldwide is how best to care for older people, whilst limiting the demand for expensive hospital and nursing home beds. One solution is the development of digital technologies that support care remotely, often in the patient's own home; commonly called telehealthcare. Despite a strong policy push and the espoused potential of this technology, uptake has been slow with health services yet to show that implementation of digital health technologies can result in a significant and sustainable shift in care services from hospital to home [1].

We have been conducting research into the progress of the UK's telehealthcare programme since its inception [1–3]. In terms of understanding and changing this position, the UK has taken a strong lead, particularly with the commissioning of the largest randomised controlled trial of telehealthcare services; called the Whole System Demonstrator programme [4]. Our results from this study have yielded mixed results [5–8]. The findings presented here represent another untold facet in telehealth story by considering how staff tasked with adopting this new technology responded to this demand.

Health services constantly need to innovate and evolve to survive, while keeping their staff on board. However, we know that adopting innovations that essentially alter or are in conflict with organisational members' current ways of thinking and acting are complex; individuals need to engage in a process of negotiation to balance the demands posed by these old and new types of identity causing many planned changes to fail [9,10]. The UK public sector, in particular, is littered with high profile examples of costly digital failures [11]. Repeated attempts to produce transformational changes across this sector all demonstrate the severe difficulties associated with the introduction of new ways of working in this domain [12].

In this paper, we were interested in exploring the apparent paradox between the much heralded advantages of telehealthcare [13] and apparent difficulties in achieving wide-scale adoption of this

digital health technology. Despite a growing interest in telehealthcare, we know little about how organizational members have perceived and responded to this innovation, in terms of anticipated material changes in their work (such as interacting more remotely) and their occupational identity. Our case studies represent five large public sector health organizations. All the organisations were simultaneously charged with developing mainstream telehealthcare services. Implementation was accompanied by a list of significant changes in patterns of resource allocation, cultural changes in the professional ethos and work practices in the current form of care delivery to meet the new environmental demands aligned with the telehealthcare vision [1,3].

## 2. Theoretical Framework

In trying to unpack these innovation adoption attempts literature has elaborated that for change to succeed organisations need to go through a process of identity transformation [14]. Both managers and employees must disengage from the past and embrace the future [15,16]. To achieve this shift the cognitive template or interpretive scheme, shared by managers and staff [17] regarding the organization's visible face, activities, structures, and goals [18,19] needs to be reorientated or replaced. This reorientation typically involves "unlearning" or the "destruction" of central assumptions within the existing schema, enabling members of the organization to assimilate new beliefs and assumptions associated with the new strategy [18,20].

At an organizational level, beliefs about "who we are" as an organization reciprocally influence beliefs about ourselves. The organization creates a context for individual identity and self-beliefs, while individual identity-beliefs are the foundation upon which collective organizational identification is built [21]. Therefore, although these two aspects of identity may subsist as distinct in a conceptual level, in the social world individual and collective identities are not always easily separated; they interact to the extent that they share attributes, serve similar psychological functions (self-verification processes) and grant each other meaning [22]. It is the level and function of this dialectical relationship and perceived compatibility between them in the light of an innovation that induces identity transition, or threat. It was the expression of these concepts, embedded within managerial narratives that we are interested in.

Innovation may set about a process of disruption that alters the existing identity status quo and triggers the need for sensemaking [23]. Sensemaking is the process that fundamentally sustains and generates individual and organisational identity [14], through the creation of mutually shared understandings around questions, such as who are we, what are we doing, and why does it matter [24]. Once shared meaning or sense is broken, new sensemaking needs to take place [25].

In organisational contexts, negotiation around achieving this task largely falls to managers; their sensemaking efforts and abilities are needed to legitimate and reorientate the cognitive scheme of other employees [26,27], thus, the assumption is where managers lead others will follow. Managers need to reconstruct a meaningful framework for understanding the nature of an innovation (in our case telehealthcare) in order to maintain and generate their organisational identity in light of potential disruption [28]. As the most visible members of an organization, managers [28,29] also need to facilitate new sensemaking and organizational identification in other employees [16,30]. Fiol [14] suggests managers facilitate major identity transitions in other members by reducing the

value of the current organizational identity, before going on to provide members with something new to believe in.

In some organizations, the sensemaking of change recipients closely aligns with the vision provided by management [29]. In other cases, the initial strategy formulated by managers is merely a starting point for an employee's sensemaking [18]. An employee's constructed identity and the wider organizational identity in which they are situated are likely to overlap, but not necessarily closely align [31]. In recent debates about how consensus in sensemaking emerges, social interactions with others are highlighted as essential to this process [25,32,33]. Consensus is reached through a process of sensegiving [28]. Sensegiving is the means of influencing sensemaking in others, of shifting them towards a preferred construction of reality. Managers, by the virtue of their role, primarily take on this sensegiving task. Managers give legitimacy, face validity and desirability to the new frame [34] allowing other employees to consolidate the meanings, gain entry to new groups [31] and construct new possible and "desirable" selves [35]. People may affirm positive aspects of the organisation if it corresponds with their own cherished views of themselves, if it bolsters their need for self-consistency, self-esteem and belonging [36].

In an organisational context employees will be proactive in protecting the "target" of their ownership [37]. Experiencing psychological ownership of a shared organisational identity of a group or sub-group, with fierce group loyalty and competition between those in the group and outsiders [21] implies a feeling of possessiveness and strong emotional ties to the organisation [38]. However, if a change in work is perceived as a threat to this "target", people may resist, utilising sensemaking tasks that cognitively (and sometimes behaviourally) disengage and distance themselves and others from the proposed organisational aims. In extreme cases this dis-identification work may lead to a sense of separateness with employees actively discrediting or even breaking their ties with the organization its ideas or members [31]. Hence, by default managerial narratives and strategies to cope with unexpected or top down induced forms of change in the context of adoption of telehealthcare are the focus of our study.

### **3. Methods: Case Study Design and Selection**

We wanted to remain open to the messy reality that emerged, having said this, we also pursued pre-existing theory as the driver for our research design. Since organizational change is a process that takes place over time, we sought to elaborate a "process explanation" [39] unpacking the dynamics relating to sensemaking, sensegiving and identification over the course adoption processes covering five years.

We were concerned with assessing the impact of managerial identity on the adoption of digital health technology, thus, we needed a range of cases that would provide potential variation. The UK Government had given £80 m to public services providers in England to develop telehealthcare services. From a national sample of 151 possible organisations in England and with government advice we were able to identify a set of cases which were considered national front runners. These five sites were contained within this sample as they had a range of managerial strategies and team compositions (using either external or internal staff to organization) for implementing the change require; the development of new telehealthcare services. Identification of these five sites was done

over a six month period through the systematic use of a range of channels (sites publicizing research on a national telecare website, meetings with experts, conferences, site visits, phone calls, government databases, interviews and from project documentation). To enhance generalisability, demographic variability was also taken into account. Two sites were large counties in the south of England. One site was a large county in the north of England. One site was a large metropolitan area on the middle of England. One site was a London borough.

#### 4. Data Collection

We were given full access to the data available across our five sites and an open invitation to visit. To preserve anonymity and confidentiality we have assigned fictitious names to the sites. We used a range of ethnographic methods [40]. In each study site we attended events such as project group meetings and other strategic meetings and observed rollout of telehealthcare services and team decision-making (a total of 170.5 h of observations ranging from an hour to a whole day in duration). These observations played a fundamental role as we developed our understanding of the changes unfolding for the managers and other staff members. As soon as we gained access to the sites we attempted to identify and attend as many key events as possible in order to engage with locally meaningful practices. Each visit was recorded in field notes on the same day to record chronological progress, as well as the observational field notes of the visited sites [41]. All our visits to the sites were non-participatory in nature but we did attempt to create a sense of trust with our informants that would prompt them to freely share information and interpretations.

We relied on a number of other sources in our story building. We examined freely available documents ( $n = 17$ ) such as annual reports and management meeting minutes concerned with telehealthcare implementation. We conducted many informal discussions with managers and other stakeholders throughout the period of our study, and in addition conducted formal interviews (over five years from April 2006–June 2011).

We wanted to assure representation across the organization's hierarchy and functions, which led us to the following choices. After the managers and their teams were interviewed, we assigned a roughly equal number of interviews for each of the five sites making sure a representation of other staff were selected and matched in terms of role ( $n = 90$ ). These included local authority and health services staff. Participants were the Chief Executive and other Project Managers, Directors of Service, Commissioners and Senior Nurse Practitioners. We wanted access to those informants who were actively managing the telehealthcare implementation because of their formal position, as well as those who were identified by others as likely change recipients. This ensured we gained a well-rounded picture of adoption efforts, allowing room for resistant voices, as well as the voices of champions [42].

The interviews typically lasted one to two hours, were tape-recorded and transcribed verbatim. The interview protocol contained a number of questions regarding the sites' current telehealthcare position, likely future position, telehealthcare strategy, and the interviewees' own work roles, motivations, commitment and actions within this context. Interviewees were also encouraged to pursue any topics they regarded as relevant.

## 5. Data Analysis in Five Rounds

Our analysis followed the principles of grounded theory [43], progressing from a very detailed, empirical reading towards greater abstraction. Our practices for analyzing and presenting the data were also inspired by the qualitative work of Gioia and his colleagues [16,26,28]. The analysis progressed in five rounds. The first round involved detailed contextual analysis of past history; how previous telehealthcare change efforts had progressed. This built a baseline from which strategic progress could be assessed. We then began the process of building a grounded theory. Strauss and Corbin [44] suggest that grounded theorizing begins with a fine-grained reading of the data—a practice which they call microanalysis. We began our analysis by writing a detailed account of the current change effort from the viewpoint of managers. We sought to give a rich account of what had transpired. We catalogued and temporally ordered the data, and used published official sources to construct a recent event history of what had transpired. We coded what appeared to be important events in the implementation process. We proceeded to integrate the views of different stakeholders by using non-public texts and interviews. As the richness of our data allowed for triangulation, we augmented, criticized and structured more public narratives with non-public texts.

During the third analysis round, we coded the data on the basis of the theoretical account we had taken, with pure induction balanced against our initial sensemaking framework. The framework guided our field work and data collection, but we were cautious not to be de-sensitised. The aim was to construct new and emerging narratives. To achieve this we used a narrative strategy of qualitative process research [39], constructing multiple interwoven stories from our data. This narrative story building required that data and theory be constantly compared and contrasted. Evolving theory directed attention to the efficacy of our conclusions made while new data focused attention on the suitability of our conclusions.

Finally, during our four and fifth round of analyses, we integrated the previous rounds into an overall explanation of sensemaking, identification and re-identification and adoption success and failure at the sites, introducing our theoretical vocabulary into this framework [23,28,29]. Over a period of six months five levels of analysis and coding incorporating over 100 pages of text emerged before the final conclusions were revealed and data saturation was achieved. Overall assessments were validated by two researchers and further validated with the informants themselves. These conclusions were further validated by an independent analyst who was asked to code a selection of randomly chosen extracts (about 20%). A high level of agreement was achieved. Our preliminary findings were then further validated by being presented at twenty one conferences attended by representatives from local authorities, health authorities and the industry supply chain implementing or considering implementing remote care. There was broad agreement with our interpretations.

## 6. Findings

Firstly, we measured the rate of success of telehealthcare implementation. This is illustrated by the number of people in each site using the new service (see Table 1). User numbers is an easily comparable metric, indicative of other associated complicated organizational changes, such as the

development of new call centres, new staff roles and training to support these new users. Variation across our five sites was large. User numbers increased and strategic change successfully progressed, in Newhall and Canton, and to a lesser extent in Dinham. Samridge and Sunning failed to further implement telehealthcare services, with telehealthcare user numbers gradually decreasing (see Table 1). In an attempt to understand what may explain these differential levels of adoption across our five sites, the next sections discuss how the strength of managerial organisational identity, experiences of work process control through participation in decision making and a sense of possessiveness towards the organisation frames what constitutes “success” and determines local adoption rates of telehealthcare. Empirical evidence on the impact of organisational ownership is incomplete, but initial work suggests that extremely high levels of psychological ownership may be counter-productive when attempting to promote innovation as members may feel threatened and try to defend their “turf” [38].

**Table 1.** Telehealthcare implementation across our case studies.

<b>Study Site</b>	<b>Dinham</b>	<b>Canton</b>	<b>Newhall</b>	<b>Sunning</b>	<b>Samridge</b>
Population No. 100,000	493	1329	243	282	1059
Population type	Rural	Mixed	Urban	Mixed	Urban
Level of funding April 2006–2007	£349,004	£743,386	£147,507	£230,136	£554,023
Levels of funding April 2007–2008	£582,612	£1,245,365	£243,208	£379,716	£921,853
Total	£931,616	£1,988,751	£390,715	£609,852	£1,475,876
Additional funding secured 2008	£700,000	£2,000,000	£4,000,000	None	None
No. of users * June 2006	140	310	400	300	300
No. of users June 2008	710	1450	2401	260	233

\* Numbers of telehealthcare users include those with home monitoring systems (the frail elderly, with for example falls detectors or motion sensors) and health monitoring systems (for those chronic conditions such as Chronic Obstructive Pulmonary Disease).

The strength of managerial organisational identity was assessed by exploring each participant’s length of service, and their organisational commitment and identification with telehealthcare work [45]. This information was extrapolated from the interview data. The aim of this method was to assess participant’s strength of organisational identity and explore how they conceptualised this tie. The interviews covered questions such as the desire to remain affiliated (commitment), the use of elements of the organisation identity to oneself (identification) and alignment with organisationally shared goals and values. Finally the participant’s sense of ownership regarding their current work, the organisation and the proposed strategic change (telehealthcare implementation) was explored [37].

## **7. Managing Innovation in the Context of Identity Change**

Samridge is the case that is most surprising in terms of its failure to deliver a telehealthcare service. The site had £1.5 m of funding, an experienced committed manager and team of five support workers, yet over a two year period they managed to decrease the number of people receiving this digital health technology. The manager (Mark) was highly identified with the both

the telehealthcare work, and the organisation, “to succeed means everything to me”. He proudly described himself as actively being involved in an innovation that was distinctive, unique and prestigious and described the great value of this to others. Mark expressed being personally responsible for previous strategic successes and taking sole charge of the telehealthcare, “they need to realise that if they got rid of me the programme would collapse because I’m everything, I’m very closely identified with it.” However, the organizational decision to move forward on a larger scale, and invest large sums of funding on an expanded service meant he was no longer in sole charge.

“I loved doing the telecare work but now I’ve been told it’s going to be over my head—And now I’m not so sure I believe in this anymore—I felt happier about the changes to our working practices when I knew I had a hand in how things were being run.”

His esteemed identity, as the person in charge appeared under threat [29], through the prospect of dismantling the current scheme with another, the exact details of which were unknown to him. He expressed that the continuity and future of his role and the work of his immediate team was in jeopardy. Mark was unable to reconcile the new change with his previous role and he is inclined to distance himself from the membership that is being challenged noting an “obvious and non-negotiable mismatch” [30] between himself and the values of the organisation.

“I now longer have any faith that they know what it is they are doing—All this new health care service—It needs real staff on the ground to run it—And now they seem to not understand that anymore—And I feel they are just not caring about the people they service—And I’m not sure I want to keep going with this anymore and my values and theirs’ don’t match-up.”

Mark’s team strongly identified with organisation, yet construction of identity content is, not an individual endeavour, nor a matter of personal choice. We know that identification processes are inextricably linked to individual and organizational relations with others [46]. The making of one’s desired self at the workplace is a highly complex process and often a contested endeavour, negotiated through dynamic social interactions between group members, managers, organisational informants and other stakeholders holding differentiated positions [31,46]. Organisations are made up of a large number of groups and subgroups with different social identities and group prototypes, which provide individual members with many different opportunities for the development of new identities or joining existing organisational groups, where ingroup members share similar ideas and attitudes. However, it is the manager, usually the most visible member of an organisation, who has the power to facilitate, support or block entry to organisational groups, and, through their sensegiving efforts, provide legitimacy, face validity and desirability to belong to a group membership [31,46]. According to Mark the meanings and values associated with the new proposed telehealthcare identity are not only ambiguous but also undermine the current position and vision of the group. In an attempt to ameliorate the threat and its negative consequences Mark created a small but salient sub-group identity.

“We’ve increased our numbers of staff. We’re going to get a fifth member. We’ve got other people, but they’re, not negative as such, about the service, but I don’t think they fully understand the implications, or necessarily share our, my vision.”

Although the group identified with the organisation, work members often self-categorise first at the level of their subunit—Their department or immediate work group—Because of task interdependence, interpersonal proximity and similarity [47]. The team closely identified with Mark, and Mark’s sensegiving was highly effective. His desire to maintain control and separate himself and the team from others resonated. Once part of a desired group, people’s self-definition is enacted with reference to the group, and the member will follow the groups values, norms and beliefs [46] working in concordance with the group identity to enhance and maintain self-esteem levels. A large part of this behaviour will consist of engaging in favourable intergroup comparisons to accentuate the ingroup similarities and remain positively distinct from other groups [48]. The proposed organisational changes were translated by Mark and communicated to his team as a threat to the group’s systems of values and beliefs. Mark’s status and power legitimised his right to pass on a negative judgement about the proposed organisational changes creating a temporal sense of loss and anxiety within the team which he successfully dealt with by insisting that the team should protect themselves from others to maintain control. A type of battle mentality emerged, a “them and us” divide that had not existed before. A subgroup of aspirational remote care experts ready to ‘fight’ their battle and lead implementation in their own way emerged.

“I don’t want to work with others on this anymore—I feel we are the only ones who understand the nuances of implementation and other groups just don’t really get that—So I fight to keep this here and if I can’t then I think we will just give up.”

Over time this “giving up” and overall lack of identification with the new telehealthcare led to implementation failing to progress (see Table 1). Mark and his team made no attempt to widen participation to others, there was a lack of cooperative spirit, with rigidity and the embattled attitude eventually leading to a reversal in telehealthcare uptake.

In contrast, staff at Sunning appeared from the outset to have low organisational identification with the organisation and with their immediate work group and little commitment to telehealthcare. This appeared largely due to organizational restructuring, which happened just before and during and the study period. Nearly all staff had had to reapply for their jobs, with heavy job losses reported and staff reporting “it is the worst time ever known here”.

“It hasn’t been easy because everyone is in a state of flux at the moment. We are going through a big structural reorganization. So everyone working for health is very nervous at the moment because they know that jobs are going to be cut and nobody knows yet who.”

Staff were disillusioned, and by the end of the study identification and trust within the organization and telehealthcare work was at “an all-time low”, with staff expressing that the reorganization meant the end of working life as they knew it, and many staff leaving of their own volition. In the chaos the manager in charge of implementation was replaced twice.



“The idea of working together and all that working practice stuff, is really key in getting to where we are, but he’s now been replaced by someone else. It’s that’s understanding, all lost, it was kind of like we had to start again, and we just can’t do it.”

Staff turnover meant that sensemaking and sensegiving did not have continuity, and staff became largely indifferent to the telehealthcare, apart from how it affected them personally. There was also a growing lack of any belief in telehealthcare or trust in the organization’s agenda surrounding the technology. Without individuals’ to champion the benefits or the technology people appeared reluctant to believe in it or engage, resulting in very little being achieved.

“We have got kind of rogue voices, who were quite against doing anything at all. They would turn up to meetings but didn’t want to get involved and wouldn’t sign up to anything.”

In Dinham the “battle” to provide people in the district with basic provisions was spoken about with evangelical zeal. Staff who worked at Dinham were “on a mission” and were proud to be “making a difference”. The high level political support at the time pushed telehealthcare services further up to the local agenda and added not only to staff commitment and pride but also to the “determination” to succeed.

The manager (Peter) in charge of telehealthcare implementation and the chief executive officer expressed enthusiasm for the task ahead, but there was a lack of knowledge about how the task could be achieved. Peter was given operational responsibility for achieving the strategic change but early on experienced a loss of credibility within his team. With the stakes high due to the concerted political interest Peter also expressed internal doubts about his abilities. External credibility with colleagues was further dented by a failed bid to gain additional funds from the UK Department of Health. A lot of effort had been put into the bid and failure was taken badly. As stated by one senior practitioner and member of the team the overall impression was that Peter was a “*good bloke*” but lacked the experience needed for the task of implementing telehealthcare organization-wide.

This lack of belief made Peter vulnerable and the task of implementing telehealthcare and sensegiving the benefits of this change to other employees hard. Other staff did not take Peter seriously and some organizational members were openly hostile. This lack of trust in Peter’s abilities and uncertainty about the innovation itself largely contradicted the actual progress made over the course of the study (see Table 1). Despite the setbacks and with political support on board there was significant progress, but overall rate of success was hampered by Peter’s own lack of belief in his ability to lead, and offer sensegiving that provided members with a sensemaking foundation from which to move forward. As Weick, Sutcliffe and Obstfeld [24] explain, sensemaking is driven by plausibility rather than accuracy. The drafting of an emerging story requires robustness, in order to be resilient in the face of criticism. The sensegiving did not appear enough to counteract growing scepticism in the value of telehealthcare care and concerns about how it would impact on people’s work. A process of excitement, and action was, thus, followed by feelings of exhaustion, uncertainty, inaction and gradual loss of confidence in dealing with the complicatedness of the task in hand [49]. Realisation that building a single and coherent

organisational vision may not be either plausible or desirable in the current context emerged as infighting and worry about the “new roles” set in.

“There’s the S curve where you have a rise in expectations and excitement and then you have a huge trough where things start going wrong and you know, people are getting tense and nervous.”

In Newhall the chief executive office decided to parachute in an external consultant and his team to drive the change through (see Table 1). Newhall had a highly identified and loyal workforce. Newhall is one of the most deprived areas of the UK, with high crime and a prevalence of older, sick people (those too poor to move away). Staff in Newhall were, again, highly committed to improving things. The chief executive in Newhall was highly respected and his choice of management strategy was universally accepted by other staff and paved the way for a radical programme of change.

“We are trying to drive this programme so it becomes business as usual from the start, and the last thing I want to do is set up separate organizations because then it becomes self-perpetuating, and the whole idea and the whole reason why we use consultants is so that a future point we can take them away and share it to everybody else—And drive it into the mainstream.”

The consultant and his team did not identify with the parent organization, seeing themselves as outsiders. The lack of a strong organisational identification allowed the external team in Newhall freedom to quickly set about dismantling the existing interpretive scheme, getting rid of areas of doubt about technology myths and “hidden management agendas” winning over sceptics. By interpretive scheme we mean organisationally shared central assumptions and beliefs about the organisation that define and legitimise its goals and activities [19].

“I feel it’s up to me to decide how to make this programme work—And so I am going to led on this and make it work for us—I will decide how we will deal with sceptics and I will sort out the men from the boys when it comes to delivering the new model of care—And it will be a new model—My new model.”

Despite this freedom, there was concern over employee resistance. The team expressed how they worked tirelessly to provide new roles and identities and reduce any anxiety related to changes in work practices [50]. The consultants addressed feelings of uncertainty regarding individual’s professional roles by emphasising the importance of individual jobs, and the organisation’s need for employee input to decision making, in terms of building an increasingly vital and forward thinking organisation that would serve the future needs of the community beyond the project deadlines. The consultant (Matt) clearly stated that he felt his job was to align employees with the ethos of the organisation and its goals, as opposed to his own goals.

“I feel we need to get people on-board with the strategic vision around all this—It’s not about my way but about the way forward for this organisation and we need everyone to start leading on this and getting exciting about it.”

Managerial sensemaking activities were mobilised on a huge scale, with different managerial strategies employed at different phases of implementation. In the early phases of implementation rhetorical and symbolic strategies were widely used. New names were given to the initiative, and media and marketing campaigns were started. Sensegiving focused on persuading other stakeholders to embrace the new change, with telehealthcare positioned as a new and exciting development that would enable people to live better lives at home. We observed negative rhetorical strategies [14] (p. 664), with no attempts made to devalue previous working and care delivery processes.

At a later stage rhetorical strategies were further supported by shared social actions, such as the creation of new work roles, and involvement of different stakeholders in tasks such as workshops and training. In the final stage of change, for identification to become secured and newly learned understandings to gain purchase both types of strategies were consistently evoked, allowing for no backward slippage [28]. These sensegiving tasks (such as workshops, training days, conferences and media communications) provided stability and a framework for schema replacement and the development of a new organisational identity. Staff started to think of themselves as part of the scheme and identification and inclusion in the telehealthcare initiative quickly became a desired goal.

“I think it gives the work status and gives us an edge if you like. We are seen as being forward thinking and as being at the front. This is good for everyone here so I said count me in.”

These strategies were most effective when combined with a fast pace of the change [28], and the sheer level of combined activity was perceived as critical, leaving members no opportunity to reflect or fall back on previous ways of working. Alongside the changing political and local narratives, the innovation itself and its desired outcomes evolved. Telehealthcare was initially concerned with delivering pilots, but to be scaled up it also needed to be a clinically safe alternative and a potential money saver. Matt expressed that this was hard message to sell.

“There’s a big divide. We’ve breached it in many places, but it’s hard work and it’s very quick to open up again if you don’t keep looking after it.”

In Canton, like Newhall new managers were brought in to lead the change, but unlike Newhall staff were new internal members of the organisation. The CEO felt that new people could be “different enough to have the freedom to innovate and actually show that different things will, and can work. And they do tend to learn from each other”.

The organisation was perceived as highly innovative and as having a charismatic and entrepreneurial leader. This leadership had brought positive and radical changes to the organisation. The sheer force of the CEO’s personality and trust in him allowed the new appointments to be initially accepted without resistance. The new managers took full advantage, solidifying their new role with action. They requested funds (>£2 m), and they set about buying large amounts of telehealthcare equipment. Despite the CEO’s support this action was poorly received, especially when the process of implementation slowed. Trust between the managers and other members of the organisation was under scrutiny, as the technology failed to live up to expectations and deliver

expected benefits in the time frame originally espoused. New “them and us” divides started to emerge. The new roles had tenuous legitimacy, and the managers received little support from the internal staff who perceived them as being “for themselves” rather than working for the good of the organisation.

“Those people do focus on the equipment and buying things because it looks so good. You see something and say, that’s great. But what are you going to do with it? They don’t actually know! It was a bit toys for boys, and I’m sceptical you have to do a lot of work to integrate that technology into the actual service delivery to achieve the value.”

The CEO response was to create four new posts to support the change. These posts were filled by esteemed internal members, with their work role and duties reassigned. The creation of the support posts had strong symbolic meaning, giving needed legitimacy to the new work. The action enabled the work to be seen as more integral to the organisation. New levels of personnel also enabled the managers to increase their sensegiving activities, with a large media campaign extolling the virtues of the new service model for clients.

“We’re on the journey of trying to change our approach-to how we view the public, how we’re dealing with our resources, how we try and create and provide opportunities for people to be more independent. And it’s about the role of what we can offer them in support of that.”

This new sensegiving moved away from previous dialogues concerning the “extravagant spending” with the change successfully reframed as “a change for good”. With these new activities further implementation progressed well.

## **8. Discussion**

By studying the messy process of organisational identity and its impact on telehealthcare adoption, not just as the change is being instigated but throughout the change period and across five large public sector organisations, we develop new insights. Our findings support the argument that the dynamics between individual and organisational identities both support and undermine digital technology adoption efforts. Levels of ingroup identification played a key role in determining how the proposed organisational change (telehealthcare) was perceived, the levels of threat experienced and the choice of responses for improving the integrity of the organisational identity and the local management of implementation.

In our case study Samridge, the manager who most strongly identified with the innovation felt threatened by the intended change [14,29]. Via sensegiving this threat was then transferred to an equally strongly identified workforce. The high level of agreement that telehealthcare was threatening resulted in the manager and his workforce coalescing to form a united front that prevented further adoption. Many studies have described sensemaking efforts in the context of externally induced unfreezing [14,16,29]. In this case, sensemaking was not focused on actively unfreezing the prior interpretative scheme but appeared collectively used as a method of undermining and creating more scepticism, whilst legitimating specific self-conceptions [51]. All

attempts to alter managerial control with organization-wide standards and procedures were negatively communicated and seemed largely ignored. The impact on telehealthcare implementation was devastating, despite £1.5 m of additional funding, there was a reduction in telehealthcare users from 300 to 233.

We found organisational attempts to redefine work roles and loosen identification were inhibited by past experience and already solidified identities. The strategic decision to legitimise early work by giving individual managers increased status and control was problematic and painful later on. Initially, the actions led to an increased passion of the telehealthcare initiatives, with managerial identities and the telehealthcare increasingly intertwined. This deep connection and ensuing state of psychological ownership initially enabled the organizations to drive forward—people were enthused and committed. Later the move from pilot projects, run by individual managers and self-managing teams, to organization-wide initiatives required an individual's shift in identification and ownership; either explicitly via relinquishing control of the decision-making to another authority or through more tacit forms of control over problem definition, implementation strategy and execution. At this point strong identification and possessiveness became problematic. Being seen as a pivotal part of the telehealthcare implementation became a preferred self-conception [35,46], a valued source of identity meaning and self-esteem. Moving to organization-wide development was threatening; it meant the potential loss of this desired self. In addition to individual identity threat, the organization's identity was often damaged by the technology itself not matching many of the apparently over hyped expectations. We observed many people excitingly engaging, then later emotionally disengaging, as the “*gut wrenching reality*” of poor adoption outcomes became “*too much to bear*”. Managing expectations and supporting a collective (organisation wide) rather than an individual level of psychological ownership from the start might have lead to better implementation outcomes.

In Dinham, organizational identification was strong, both individual members and the manager in charge of leading the change were committed to telehealthcare, supportive of the innovation and proud of the organizations achievements. Yet, identification processes negatively impacted on strategic change, initially at a localised level. This localised effect then spread across the organization. The problem was situated in a lack of trust in the manager (Peter) assigned with the task of implementation. Identification is based around trust [52]. Trust is a psychological state of positive expectation about another's motives and future actions [53]. Staff did not believe in Peter, and subsequently they did not believe in the telehealthcare technology, despite the fact there had been some progress. This led to Peter questioning himself and created a negative interactive spiral, with implementation strategies too risk adverse and conservative to create the environment to support wide level of implementation required by the organization.

Similarly, in Canton, trust and the perceived legitimacy of the managers became an issue when implementation slowed. Newly appointed managers had the freedom and vision to move beyond traditional organisational boundaries, without feeling personally threatened by the change. However, this strategy carried risk. Staff who do not highly identify with organisation can be perceived by other members as “outsiders” and as lacking legitimacy. This inherent danger was acknowledged and addressed in Newhall right from the outset. Managers in charge of

telehealthcare were external consultants, who capitalised on their positions, in not being strongly identified or strongly identifying with the extant scheme. They set about successfully dismantling the old scheme and setting up the new, with rapid and radical action. Throughout this action, the managers were very mindful of the need to build trust, and internalise ownership of the change [37], with a large range of sensemaking tools and co-opted actions utilised to strengthen the legitimacy of the new interpretative scheme.

To replace the old scheme “*people needed something new and bold to believe in*”—telehealthcare care needs to deliver promised benefits and quell concerns about future working practices. To create this whole new bold world, a new language was utilised and further reinforced with behaviour and symbolic artefacts. For example, the organizations gave the telehealthcare initiatives new names, gave members involved important sounding new titles (*i.e.*, Telecare Programme Director) engaged in widespread marketing to constituent users and other stakeholders, and gave staff new roles. The tactic was one of inclusion [26], the action to work hard and to work quickly, leaving no room for reversal. This risk was conceptualised by managers in both Newhall and Canton. Until the new identification was concrete, the residual effect of the previous cognitive scheme remained strong, so unattended members could quickly fall back on previously learned or relatively automatic behaviours and ways of thinking, even after the change process was enacted.

## 9. Conclusions

Crucial to the process of achieving acceptance of digital health technologies is the process of negotiation, of sensemaking and sensegiving between managers and members. As the case of Sunning demonstrated, some level of identification with the technology is required for sensemaking and sensegiving activities to take place. Additionally, with the technology itself also delivering the expected benefits. The final outcome depends on managers and members negotiating and renegotiating what the technology means to themselves and others [42,50]. Alignment and consensus needs to be reached for strategic action to take place, but it is the ongoing sensemaking and sensegiving negotiation aspect process that is pivotal to make it a success.

## 10. External Generalisability

Our focus has been on the relationship between identification and telehealthcare in public sector innovations. The unique nature of our setting and our inductive qualitative inquiry does not mean that “naturalistic generalization” is not plausible and some knowledge cannot be transferred from our study sample to a wider population which may have subtle differences in other organizations and settings. This said our sample was large, theoretically informed, and appropriate to our research question. We ensured rigour by sampled from different organizational levels: senior management, middle management, senior and operational practitioners with our data not limited to one organization or profession. But our data collection was not exhaustive, and we adopted qualitative methods and used purposive rather than random sampling. To overcome these limitations, we maintained a systematic approach to our research rigour at every stage of the study, in our design, sampling, analysis and interpretation.

## Acknowledgments

This article is based on research projects funded by the EPSRC funded Health and Care Infrastructure Research and Innovation Centre (HaCIRIC) and the Department of Health, UK. The views expressed are those of the authors and are not necessarily those of the funders. We are also extremely grateful to the participating case study organisations for their help, and to all the interviewees for their time and interest in the study. We are also grateful to members of the remote care community for their continuing support in our research.

We also thank the independent referees for their helpful comments on an earlier version of this paper.

## Author Contributions

Jane Hendy and James Barlow conceived and designed the study. Jane Hendy and Theopisti Chrysanthaki have collected the data, performed the analysis and drafted the manuscript together. All authors have contributed to interpretation of findings, commented on drafts produced, read and approved the final manuscript.

## Conflicts of Interest

The authors declare no conflicts of interest.

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## Exercise as Labour: Quantified Self and the Transformation of Exercise into Labour

Chris Till

**Abstract:** The recent increase in the use of digital self-tracking devices has given rise to a range of relations to the self often discussed as quantified self (QS). In popular and academic discourse, this development has been discussed variously as a form of narcissistic self-involvement, an advanced expression of panoptical self-surveillance and a potential new dawn for e-health. This article proposes a previously un-theorised consequence of this large-scale observation and analysis of human behaviour; that exercise activity is in the process of being reconfigured as labour. QS will be briefly introduced, and reflected on, subsequently considering some of its key aspects in relation to how these have so far been interpreted and analysed in academic literature. Secondly, the analysis of scholars of “digital labour” and “immaterial labour” will be considered, which will be discussed in relation to what its analysis of the transformations of work in contemporary advanced capitalism can offer to an interpretation of the promotion and management of the self-tracking of exercise activities. Building on this analysis, it will be proposed that a thermodynamic model of the exploitation of potential energy underlies the interest that corporations have shown in self-tracking and that “gamification” and the promotion of an entrepreneurial selfhood is the ideological frame that informs the strategy through which labour value is extracted without payment. Finally, the potential theoretical and political consequences of these insights will be considered.

Reprinted from *Societies*. Cite as: Till, C. Exercise as Labour: Quantified Self and the Transformation of Exercise into Labour. *Societies* 2014, 4, 4466462.

### 1. Introduction

The recent increase in the use of digital self-tracking devices has given rise to a range of relations to the self often discussed as quantified self (QS). In popular and academic discourse, this development has been discussed variously as a form of narcissistic self-involvement, an advanced expression of panoptical self-surveillance and a potential new dawn for e-health. This article proposes a previously un-theorised consequence of this large-scale observation and analysis of human behaviour; that exercise activity is in the process of being reconfigured as labour. This is not, however, an ontological argument suggesting that exercise is inherently labour. Rather, it is proposed that in our present context, exercise and labour are in a process of merging in such a fashion that in a short space of time, the two may seem inseparable. This position was arrived at by thinking through the similarities between the activities undertaken by self-trackers and those discussed as “digital labour” [1]. A significant amount of the novelty of this position is derived from focusing the analysis on the strategies of the corporations who develop and control self-tracking devices rather than the users themselves. The main reason why it is proposed that digital tracking devices are having a considerable impact upon how exercise is understood is

because of their ability to objectify and standardise the activities and capacities of heterogeneous bodies in such a fashion that value can be extracted.

This article will first introduce QS and consider some of its key aspects in relation to how these have so far been interpreted and analysed in academic literature. Secondly, the analysis of scholars of “digital labour” and “immaterial labour” will be considered in relation to what its analysis of the transformations of work in contemporary advanced capitalism can offer to an interpretation of the promotion and management of self-tracking of exercise activities. In the third section, the analysis will be built around two key analytical axes of a thermodynamic model of energy and that “gamification” and entrepreneurial selfhood are proposed as the ideological frame of commercial interest in self-tracking. Finally, the potential theoretical and political consequences of these insights will be considered.

## 2. Quantified Self

There has been a significant increase in the use, and particularly the sale, of devices or smart phone applications that enable the tracking and analysis of various aspects of everyday life. Most prominent amongst these are devices, such as the Nike+ Fuelband, FitBit and Jawbone Up; bracelets with built-in accelerometers that can track the distance the user has travelled, how many steps they have taken and other aspects of their activity. These activities are transformed into digital data, which are uploaded to servers owned by corporations, where they provide users with tools to analyse their progress and share their information with other users. In exchange for these services, the corporations collate data on their users, which can be used for various marketing and other purposes. A number of groups have developed around the use of such devices, most prominently a loose global network of quantified self “meetups” or “show and tells”, during which users of devices or techniques present the novel ways they have developed to track, analyse and interpret their bodies, moods and other aspects of their lives.

These devices and their users are of increasing interest to academic researchers, and work has been conducted particularly in the field of human computer interaction [2], which has explored the potential of applications for tracking anxiety [3], sleep [4] and the relationship between health tracking and social networks [5]. The majority of the work has developed out of previous analyses of e-health and m-health predominantly in health promotion and health communication circles [6]. Some literature has focused on the potential for automisation, personalisation of information or prompts and the development of online support communities [7] (p. 330). A range of studies has explored the efficacy and potential of dietary and physical activity interventions through digital tools [8–12], and the wide-ranging implications of “Web 2.0” technologies have been surveyed [13]. Some ethnographic approaches to the use of information technologies in a healthcare setting have been attempted, in particular analysing the ways in which they are implicated in social practice [14], although this approach has not yet been taken to the more informal and commercial technologies and practices central to this study. Even studies focusing on “consumer e-health” have not so far dealt with the use of digital data and health data collection devices [15].

Although published work in the social sciences and humanities so far is limited, there have recently been a number of conference presentations that have often focused on surveillance [16], as

well as notions of the “calculating self” [17] and the relationship between self-quantification and neo-liberal philosophies [18]. In the still relatively sparse published material, the theoretical implications of the use of such methods of digital self-analysis has been explored in relation to issues of surveillance and self-surveillance [19–21] and notions of “gamification” [22]. Perhaps the most well-developed published sociological work is that of Deborah Lupton, who has suggested that self-tracking and QS can be read in terms of:

- A “body-machine” metaphor with the body defined in terms of quantified “inputs” and “outputs” with self-trackers positioned as “experimenters” on their own bodies [23] (pp. 26–27).
- An expression of neo-liberal entrepreneurialism, enabling self-maximisation and promoting self-critique and responsabilisation through the presentation of “objective” measures of performance [23] (p. 28).
- Practices of “prosumption” characteristic of the use of Web 2.0 in which users are both consumers and producers of digital media content, which is the context for the constitution of virtual and physical communities [23] (pp. 28–29).
- A means through which a particular kind of reflexive approach to the self is enabled through the analysis of data and the imperative to control these data and oneself [23] (p. 29).

While I agree there is a lot of potential in interpreting self-tracking activities along the above axes, and I would consider this article to complement these approaches, there is an important aspect of such practices that has yet to be theorised. This supplement to the above analyses was arrived at largely through an engagement with the literature on digital labour.

### 3. Digital Labour

While all of the devices that are used for exercise and health tracking, and some of the apps, generate income through sales for the corporations who provide them, it is clear that the data that are produced are also valuable. Some prominent figures in QS have been calling for the companies who produce the devices and apps to allow the users greater ownership over their data [24–26]. Currently, the data generated through tracking are tied up within corporate walls, making it difficult for individual users to merge data from different devices in order to gain a more holistic picture of their health. Nike, Jawbone and the other corporations have so far not been enthusiastic about doing this. In recent years, the value of user data to corporations has become clear. While it is not yet fully known how corporations are using these data, Nike and Fitbit have both stated that while they do not sell personally identifiable information, they may do so with aggregate data or share with others within their “corporate umbrella” [27].

While this kind of sharing could effectively function as the *de facto* sale of commercial data, clearer sharing between companies has recently been unearthed. A study of twelve mobile health and fitness apps conducted by the U.S. Federal Trade Commission found that user data were disseminated to seventy-six third parties, and one app in particular sent data to eighteen other entities [28]. In addition to information, such as names, email addresses and usernames, twenty-two of those third parties received details on consumers, such as exercise information, meal and diet information, gender and geo-location [29]. A similar study by web analytics and privacy group

Evidon commissioned by the Financial Times found that the twenty most popular health and fitness apps share information with almost seventy companies. In particular, MapMyRun was found to transmit data to eleven companies, some of which were advertising firms [30].

Another route by which these data may be shared is through corporate takeovers. When fitness tracking app Moves was purchased by Facebook in April, 2014, they announced that their data would not be “commingled” with one another. Within two weeks of the purchase, they changed their terms of service and privacy policy to state that they will share data with Facebook and their other affiliates [31]. Perhaps most telling, an analysis of the privacy policies [32] (pp. 73–78) of many of the most popular health and fitness tracking apps and devices found that most were ambiguous on whether they permitted sharing of user data, with most allowing “non-personally identifiable information” to be passed on. Such aggregated data would be of great value for advertising. Corporations have not divulged for what purposes these data are being used, but we already know that the billions of dollars that companies, such as Facebook and Google, have made over the last decade have been generated largely from selling advertising space on the basis of data collected on their users. The character of Web 2.0 media is such that users are usually both the audience for, and producers of, media content and so are therefore targets of advertising and responsible for drawing in an audience who is exposed to advertising.

A significant literature has developed trying to understand the implications of the use of this “digital labour” or what Tiziana Terranova [33] called “free labour”. Terranova has suggested that the kinds of activities conducted online are symptomatic of “an acceleration of the capitalist logic of production” [33] (p. 46). The profitability of sites, such as Facebook, is dependent upon the users and “the cumulative hours of accessing the site (thus generating advertising), writing messages, participating in conversations and sometimes making the jump to collaborators” [33] (p. 48). This “free labour” generates vast amounts of income, but is not paid, because the corporations have successfully convinced users that it is leisure, not labour, through an erosion of the distinction between work and play [1] (p. 2) and the formation of what some have called “playbour” [34]. The clicks, “likes”, purchases and posts performed by users as part of their everyday usage of the Internet provide valuable data, which can then be sold on to advertisers.

Critiques of digital “free labour” have been significantly influenced by autonomist Marxist and *Operaiismo* work on the “social factory” [35] and “immaterial labour”, which tried to deal with the consequences of the decline in traditional forms of productive labour in Western countries and the rise in knowledge economies. As described by the autonomists, the context in which “cognitive labour” has increased in prominence can be characterised by the emergence of increasingly precarious forms of intellectual and affective labour. The rise of this kind of labour has seen the dismantling of the structured, bounded, restricted, waged workday governed by rules, obligations and expectations [36] (p. 26). The twentieth century, “modern” form of work organisation is being replaced by decentralised, temporary employment in which work is often intricately intermingled with creativity and self-realisation, making it increasingly difficult to differentiate between work, leisure and individual life projects and easier for corporations to benefit from “free labour”. The analysis of “digital labour” and that of the autonomist Marxists is predicated on the assumption that labour is not only that which is paid formally through wages. Rather, many forms of activity

generate value, and there are forces at work that coerce people into accepting the necessity of engaging in such productive activities for little or no pay.

The theoretical approach taken in this article has some affinity with that in studies of the “commercialization of leisure time”, which highlights not only that the line between work and leisure is increasingly blurred, but that the notion of leisure time itself is at least partly a product of the capitalist organisation of work [37]. Capitalism has reformulated people, not only as workers, but as consumers who decreasingly have the means to engage in leisure activity without consumption. Thus, the commodification of leisure time is seen as being intimately linked with proletarianization and the extraction of surplus value [38] (p. 218). Moreover, the activities of leisure come to increasingly resemble those associated with work; this fusion of “working time” with “leisure time”, both for worker and capitalist, is aided by the kind of work associated with “immaterial labour” [39] (p. 98). The contemporary orientation of capitalism towards the extensive appropriation of subjectivity and social relations that is captured in the notion of immaterial labour [40] finds particularly fertile ground in the digital world [41].

The fundamental aspect that is of significance for this article is the creative and open view of what can be defined as labour in the above analyses. In one sense, digital labour can be seen merely as a particularly advanced form of the division of labour dominant in the twentieth century, with the individual tasks of writing posts and liking photographs distributed between many different people. This is, however, quite different from a traditional factory production process in which the product is designed as an end-point and the production process broken down into individual elements that are distributed among many hands, because the product of most digital labour is data on its own producers. Even the most complex and advanced products of conventional labour are not as inherently tied to their distributed production process as the data generated through digital labour. In very few circumstances could the product of digital labour exist as a valuable commodity outside of the processes of its own collective production. The production of digital labour is its product. Before applying this analysis to digital self-tracking of exercise, it must be established precisely what is meant by labour in this case.

In the following section, I will describe how a similar process of the accumulation of labour in order to enable its standardization and quantification is being applied to exercise activity through the use of digital self-tracking devices.

#### **4. Self-Tracking**

With the use of digital self-tracking devices, we are currently witnessing the transformation of individual health activities into quantified forms ripe for the extraction of value with a variety of health apps and tracking devices. We can easily see exercise in any form as a type of “formative activity”, which, as Sayers [42] (p. 435) states, could be to “change the character of animals or people” as much as to give form to raw materials. It is clear that people see their achievements in exercise (whether in the form of medals or rankings in professional or amateur sport, lifting particular weights or running certain distances) as a certain kind of objectification of their labour, which they recognize as embodiments of their abilities. While exercise may not always be productive of economic value, it certainly often produces objectified embodiments of the labour

exerted and entails shaping and changing the character and body of a person, usually one's self. While there are many kinds of satisfaction that can be derived from exercise, certainly a major one would seem to be the objectified measures of achievements. A central aspect of the success of self-tracking devices and related analytical software has been virtual versions of such measures of achievement. Many applications offer "badges" or "medals" for achieving goals, with some, such as Strava, encouraging competition by awarding titles, such as "King of the Mountain", for the quickest time cycling up a particular hill [43]. The satisfaction gained by some in attaining such achievements is clear, and the use of such methods has been called "gamification", to which I will return below.

The quantification of particular exercise activities for individuals, then, has benefits that are largely consistent with older analogue forms of self-tracking and quantification, such as measuring distance run on a map, counting and logging the amount of press-ups performed or the logging of scores and positions in a squash or football league [18,44]. Digital self-tracking systems automate many of these processes, enable more minute measurement (in some cases) and, in particular, enable a greater amount of people against whom performance can be compared. The benefits to corporations are, however, of a completely different order: the commodification of exercise activity. Previously, the commodification of exercise activities had always taken a largely indirect approach. To take running as an example, capitalist enterprises have made money from running as an activity through the marketing of products, such as running shoes or t-shirts, which are purported to improve performance or make the activity more comfortable.

Through the large-scale quantification of running enabled by digital tracking devices, however, the activity itself is being turned into a form that is amenable to the extraction of value. In the past, the actual activity of running was only of value to the individuals themselves, and this could only indirectly result in economic value, except for professional athletes. When exercise activities are quantified in a standardized form that is amenable to comparison and accumulation, corporations can use the associated data in order to extract surplus value. Just as the clicks performed by individual Facebook users contribute towards the production of useful data for advertisers, so do the exercise activities performed by users of Fitbit or Track My Run. We can, then, see the quantification of exercise activities through digital self-tracking as a method of enabling the "accumulation of labour" in order to prepare it for the extraction of surplus value. Users of such devices have thus been convinced to pay for the chance to give away their productive labour to corporations who will use it to generate customer profiles to be sold to advertisers who will then target the users with more products.

What are the consequences of a theoretical approach that conceptualizes the labour of self-trackers or self-quantifiers as labour? To my mind, this kind of analysis is necessary regardless of how we might like to conceptualise exercise activities that are tracked; they are labour, because the corporations are treating them as such. Surplus value will be extracted from these activities by corporations, as if they were work; if we do not recognise it, then we cannot challenge it. To approach digital self-tracking of exercise activity as a form of labour, therefore, is to "follow the medium" [45] (pp. 26–27). This may potentially lead to a reformulation after which (at least, for some people) exercise activity is deemed to be more worthwhile if it is being tracked, accumulated



on a server and mingled with the data of other users. Furthermore, there may be further consequences (which will be explored below) with regards to what constitutes labour. Literature addressing the commercialization of leisure time [37–40] has suggested that the boundaries between labour and non-labour have been blurred; this has intensified with the commercialization of self-tracking data.

If the position presented in this paper is acknowledged, then there may be a situation of perpetual commercial reinforcement between work, exercise and advertising. The focus on productivity in self-tracking draws it conceptually closer to commercial imperatives than other forms of commercialization of leisure time, even when commerce is not directly involved. We can see this in the ways in which personal tracking and employer monitoring are converging, as exercise tracking apps are always in some sense productivity monitors. Moreover, digital and mobile productivity apps, such as DeskTime, are also increasingly being used by employers to monitor, and employees to prove, productivity. One app, iDoneThis, started as a “personal productivity tracker for weight reduction” and is now used as a subscription service business management tool. As Phoebe Moore [46] has shown, such techniques and technologies are being used by a variety of large and diverse organisations, such as Tesco, Amazon and the Defense Advanced Research Projects Agency, to track the productivity and health behaviour of employees in order to intervene and improve both. These initiatives are, however, not simply panoptic, authoritarian surveillance by employers. Rather, they are couched in terms of a mutually beneficial situation that improves the health and wellbeing of employees, as well as increasing productivity and lowering costs for employers [47,48]. While these “corporate wellness” strategies emphasise that employers must take action, this tends to be in the form of enabling and encouraging “complete lifestyle and behaviour change” [49] in employees.

Those concerned with employee health have discovered useful tools in digital tracking technologies with “employee wellness programs” being reported to be one of Fitbit’s fastest growing areas of expansion [50]. The data produced by devices, such as Fitbit, are conducive to existing techniques of corporate management in which workers are managed in terms of their quantified measures of productivity. A corporate wellness program implemented by BP America, which distributed free Fitbit devices to employees, spouses and retirees, helped to reduce their healthcare costs to below average growth rates in the U.S. [51]. In these cases, any line between what is beneficial for the profitability of the company and the health and wellbeing of the employee is thoroughly blurred, and as the health data generated on employees become more comprehensive and thoroughly integrated into the financial concerns of the company, the distinction will become even hazier.

This is, then, perhaps best characterised as “syndromic surveillance”, or the real-time monitoring of patterns through “automated data acquisition” [52], which has brought together health and commercial data in new ways. Public Health England conducted research [53] that drew on supermarket purchase data largely from loyalty cards to identify the supermarkets that had the highest levels of purchases of “unhealthy”. Their analysis was used to target interventions to reduce obesity. It has also been reported [54] that data brokers are selling consumer data on transactions to healthcare providers, which is being used to create profiles on current and potential patients. These

data may include purchases of food and cigarettes, as well as gym memberships. The distinction between health and commercial data is becoming unclear, and the techniques of profiling and prediction used by marketers, healthcare providers and public health are converging. A potential outcome of this could be that our health, and potential future health, will increasingly become defined in relation to complex data that we generate in a variety of different contexts.

As I see it, this article complements and adapts the four key aspects (outlined above) of Lupton's analysis of self-tracking: that there is a "body-machine metaphor" at work; it is an expression of "neo-liberal entrepreneurialism"; it is characteristic of "prosumption" practices; and it is an enabler of a particular approach to self-reflexivity [23] (pp. 26–29). By approaching the exercise activities associated with self-tracking as a form of labour, these four analytical axes are modified slightly. It is on the first two ("body-machine metaphor" and "neo-liberal entrepreneurialism") that I will concentrate, however, as these are the most significant to this analysis.

## 5. Thermodynamics and "Gamification"

The body machine metaphor suggested by Lupton [23] (pp. 26–27) is certainly present in descriptions of QS in the media and other representations, and this may well be how many users perceive their relationship towards themselves as mediated through their devices. Lupton's use of this metaphor is informed by Donna Haraway's [55] theorisation of the "cyborg", which she used to capture the contemporary assemblages of humans and technologies. The integration that wearable devices have with the body enables the cyborg to develop ever further and to constitute new relations with the body and others. It is, however, the notion of the body as a series of codes, which Haraway proposed in relation to discourses of disease, which is particularly enlightening here. As Lupton [56] demonstrates, data produced through self-tracking appears to render the messy, disordered body as clean and orderly and give us the tools to maintain control through an objective view of the body.

While the body is often conceived of in terms of inputs and outputs of energy by individuals, the corporations, by constituting users as workers in a distributed digital exercise factory, are working on a different model. Rather than the individual exerciser being considered as an isolated, molar individual, they are seen as an expression of universal energy, as a generator of data. In order to understand this, we need to think in terms of a thermodynamic metaphor based on energy and what methods of analysis have enabled this model. According to the thermodynamic model, the universe contains a fixed amount of energy that can neither be created nor destroyed, only harnessed or not. For George Caffentzis [57], energy became central to the management of work from the nineteenth century onwards. In early capitalism, the key tension between capitalists and labour was hours worked; in the nineteenth century, this shifted to an issue of "productive intensity", or, how to transform the workers' energy into work. This was seen to be fundamentally similar to the notion in theories of thermodynamics that "if a mass is exploding, you should give it a way out so organized that it will push a piston and thus do work for you" [57] (unpagged). In order to harness this energy, there needed to be a form of analysis; it needed to be "caught, fixed, and serialized" [58] (p. 39) and could, therefore, be quantified. By making physical work able to be

perceived as a series of isolated movements, this new approach presented the human body as a “thermodynamic machine” [59] (p. 30) with “work” (in terms of labour and physics) seen as a manifestation of the “energy” that underlies all of nature. The exercise in which many people engage for fitness purposes has (in capitalist terms) been wasted for decades. Digital self-tracking is an ingenious means by which energy that is being expended anyway can be analysed and transformed into productive, profitable (unpaid) “work”.

This analysis develops the body-machine metaphor that has previously been applied to self-tracking by taking the analysis below the level of the individual body to think in terms of the energy used by collections of bodies. Thinking of the body in terms of energy or data performs similar functions as it reduces particular bodies, or actions, down to a common, universal, abstract quantifiable substance. It is possible to understand the actions of those engaged with exercise data, whether individuals, governments or corporations, in terms of the harnessing of potential energy, which requires knowledge of the energy expenditure of the individual. Furthermore, this has the impact of aggregating a population in terms of their energy. Quantifiable measures, such as those generated through self-tracking, provide the potential to compare and accumulate individuals into a generalized mass.

In order to make this labour productive, however, the corporations cannot stop at the point of merely tracking existing exercise, but must encourage exercise and structure it in such a fashion that it is useful for their purposes. The virtual achievements associated with “gamification” may be determined by what the corporations think customers want (supply and demand), but are also driven by what kinds of data they want to generate and, therefore, the kinds of labour in which they want users to engage. “Gamification” here helps to explain not only how people are drawn into engagement with systems of production, but how their “work” is managed in a decentralized, distributed “factory”. If we consider the issue of “gamification”, not in terms of the pleasures enabled (although these are significant), but in terms of the productive labour generated, then we see that “[i]t isn’t play that creates its own games; it is a game that extracts labour in the form of play” [60] (p. 74). This “gamification” can, then, be seen as encouraging a kind of neo-liberal entrepreneurial self, which is “amenable to improvement, an object of personal enterprise and work” [23] (p. 28).

We can further see the relation between exercise and labour as the kinds of “gamification” employed in self-tracking converging with that used in management practices. Some have suggested that gamification could be almost a panacea for the problems faced in the contemporary workplace, tackling stress, reduced sense of community, reduced loyalty and a rapidly changing workforce [61]. A senior Microsoft director has proclaimed that “play is the future of work” [62], and gamification will enable work to become a freeing and creative process. The rhetoric of these approaches is one similar to a gift economy, where employees giving a little extra in their daily work in return for the pleasure they gain from the experience of the game. For McKenzie Wark, however, this is a distinctly imbalanced exchange, where “what is offered is a bit of cognitive energy that performs a task some vectoral business requires, and the reward is only a formal and abstract kind of token and ranking” [60] (p. 74).

When the activities that are being “gamified” produce commercially useful data, this can be seen as a form of division of labour, which is most widely seen through “crowdsourcing”, in which a task is divided between a vast number of people in order to gain a quick or cheap result. While this kind of labour organisation has often been traded on the goodwill and enthusiasm of the public for scientific experiments and other “worthy causes”, when harnessed for commercial purposes, it can be seen as a type of “labour arbitrage” [63], a “neoliberal system of exception” [64] (p. 91) or simply work that does not need to be paid. To highlight that these data are or can be valuable to corporations does not deny its usefulness to users just as the “critique of exploitation does not devalue individual pleasure any more than such pleasures nullify exploitative social relations” [65] (p.153). Furthermore, self-tracking devices have been shown to tend towards individualization and the solidification of existing economic and political divides [66] (p. 81).

We can, therefore, see the thermodynamic harnessing of potential energy latent in the population as the labour model underlying the commercial interest in tracking exercising bodies and “gamification” and the promotion of an entrepreneurial self as the strategies through which labour value is extracted with minimal payment. It now leaves us to consider what the potential theoretical and political consequences of these insights might be.

## 6. Consequences

Some might accept the conceptualisation of exercise activities as a form of productive labour, but be less willing to deem it a significant problem, given that it is generally engaged in freely; the users enjoy and benefit from it, and users tend to be relatively prosperous, unlike some others who experience more severe extraction of their “free labour” (see, for instance, Amazon’s “Mechanical Turk” [64]). The success with which corporations have been able to convince people to reconstitute their exercise activities into productive labour and to give it away freely may encourage them to expand this project in as yet unimagined ways. Indeed, there have already been proposals to use digital self-tracking devices in order to monitor traditional workplace activities [67]. Furthermore, while the kind of exploitation of labour that is occurring in this case may not be of the most serious kind, there are structural and analytic similarities with the highly exploitative kind of labour relations, which should be highlighted [67] (p. 155). If it is agreed that these labour practices are problematic, then they would need to be tackled multilaterally. The commercialisation of exercising bodies in the form we have been discussing could have potential ramifications for how such activities are conceptualised in the long term. While I have focused on exercise in this article, it is true that any tracked movement could be considered as productive of valuable data. I have concentrated on exercise because corporations are demonstrably interested in the tracking of exercise data, which also has clear commercial value. Moreover, there are potentially specific conceptual consequences to the tracking of exercise, since, just as the constitution of a “like economy” or “click economy”, in which value can be extracted from users’ everyday interactions on the Internet required a process of enclosure, so is this occurring in the present case.

The early Internet was often spoken about in utopian terms as a free “commons”; this has now been extensively “enclosed” and turned into a private space kept within the walls of Facebook or Google. Today, the vast majority of people engaged with the Internet have many of their social

interactions mediated through commercial, enclosed spaces managed by corporations. Such corporations are only able to appropriate value through “capturing and controlling components of the productive infrastructure” [65] (p. 155) of the Internet. If a similar process of enclosure is occurring through digital self-tracking devices, the “productive infrastructure” that is being captured and controlled is, at least in part, the productive bodies of the population. These are forms of exercise that were previously undertaken, usually for reasons of health, socialization or personal development. Commercialization could have a significant impact on how such activities are perceived and experienced. Early and enthusiastic adopters of digital self-tracking already report a disengagement from exercise that is not being tracked.

The analysis in this article could make a contribution towards the ongoing theorisation of “immaterial labour” by problematizing the distinction between material and immaterial as self-tracking highlights that all of the work undertaken as “digital labour” is corporeal on some level. While “cognitive labour” has been considered to be particularly amenable to the kinds of “labour arbitrage” [64] (p. 91), which exploits “immaterial labour” through creating a “system of exception” in which particular activities are deemed unworthy of payment, the present case shows that there is nothing to stop “material labour” from being organised along similar lines. This insight perhaps points to the material aspect of all “immaterial labour”, even if, in some cases, this appears to be merely the pressing of keys or clicks of a mouse. We might, therefore, consider to what extent digital self-tracking has the potential to contribute towards resistance to capitalist appropriation. The transformation of exercise activity into a quantified form has similarities with traditional forms of labour organization in the sense that it provides a way to realize our collectivity. The value that corporations extract from exercise collectively enables users to see their exercise activities as something more than merely individual activity. Just as the “collective knowledge work” that occurs in the digital economy demonstrates the “collective aspect of labour [which] implies a rejection of the equivalence between labour and employment...[and shows that]...[l]abor is not equivalent to waged labour” [33] (p. 45), so could “collective exercise work”. The labour engaged in by self-trackers is both “knowledge work” and “physical work”, “immaterial labour” and “material labour”, if indeed we require distinctions between the two.

Those engaged in the QS community are much closer to this kind of resistance than the more casual self-trackers who use “off the shelf” devices or applications. While part of this more creative approach to self-tracking is due to the “hobby-ist” and “techie” tendencies of many people involved in QS, it is also in response to issues around the management of data. While much of the academic literature assumes that the biggest issues for those in the QS community are around surveillance and self-constitution, some of the more vocal members seem to be equally interested in the control of data. In particular, some have attempted to find ways to enable users to manage their data online through open-source software [25]. There have also been particular critiques [26] of how the infrastructure of self-tracking devices and services works. Currently, individuals have little ownership over their data, because the companies that produce each device they use want to tie users into their “ecosystems” of online analytics services and social networks. It has been proposed [26] that they should hand the data over to the users, making it easier for them to control

how their data are used and who has access to it and making it more feasible to combine data streams from different devices.

The developments discussed in this article, therefore, suggest a problematisation of the immaterial/material distinction and of what constitutes work labour. The critique offered by operaists demonstrates that the boundary between work and leisure has been collapsed and has sought to demonstrate that the activities they classify as immaterial labour are indeed labour, but a different form to traditional material labour. Their focus, however, was on the products of the labour process, in which case, approaching the two kinds of activities as distinct makes sense. Material labour produces material goods, while immaterial labour produces immaterial goods. If we focus on the process of production, however, this distinction seems less meaningful, as material and immaterial goods both require physical activity of some kind, whether this is the pressing of keys or firing of neurons. Similarly, if indeed exercise activity can be considered to be labour that produces material goods (in the form of the transformation of human bodies) and immaterial goods (in the form of data), is this distinction between material and immaterial still meaningful?

We might also consider the potential impact of this analysis on the ways in which health in general is conceptualised. If digitally tracked and quantified exercise activity can be formulated in terms of labour, does this mean that all exercise activity should be? In the case of self-tracking, it is politically important to consider this reconceptualization, because exercise activity is being structured in such a fashion as to have economic value extracted from it. While the activity of exercise has always been able to produce certain use values (e.g., improved health, development of skills), it is only because it is being tracked and accumulated along with the data of others that it is able to produce exchange value in the form of commercially valuable data. As studies have shown [30,32], data from health and exercise apps are being shared not only between entities under the same “corporate umbrella”, but with external companies. It is important to remember that it is the standardization through quantification in the process of digital tracking that enables exercise activity in this case to be formulated as a collective, distributed form of labour. This is not usually the case in everyday, untracked exercise activity, and it is probably not desirable to consider it in these terms. Significantly, the value that is produced through tracking is likely to be derived from its value in generating promotional data, and it is perhaps for this purpose that exercise activities are tracked, quantified, accumulated and analysed. Nevertheless, if the tracking, quantification, accumulation and extraction of value from exercise activity continues to grow, it is possible that the definition of what constitutes worthwhile exercise may become increasingly aligned with commercial imperatives.

As an increasing amount of exercise activity is tracked, accumulated and analysed, a conceptual distinction may develop between those activities that are and are not capable of being quantified. Might we come to distinguish between exercise that is productive and unproductive of data? This could speak of a new kind of commercialization of exercise that is much more pervasive than the production and promotion of sports equipment, for instance, but brings the bodies and movement of amateur athletes itself into the commercial infrastructure. If the actual movements of the exercising body are generating valuable data, this might change the ways in which people (as well as

corporations) engage with exercising bodies. There could be a developing expectation that we will be producing valuable data when at work, when exercising and when at rest.

## **7. Conclusions**

The few sociological approaches to digital self-tracking have tended to focus on surveillance or the micro-level impact on individuals and their relationship to the self. These have been valuable and look likely to inspire useful empirical work; however, a focus on the macro level tactics of the corporations who are largely in control of the data provides different insights. By considering self-tracked exercise activity in terms of its corporate value, we can see how it is digitized, quantified, accumulated and analysed in order to generate commercially valuable data on the population. These data are particularly valuable to the corporations who are collecting it, because it has been ideologically constituted as “not work” and, therefore, not being worthy of payment. It has been suggested above that there are “structural similarities” between the “digital labour” or “free labour” that is conducted online and the digitally-tracked exercise activities of users of self-tracking devices. When approached through a Marxist frame of analysis, it is possible to see the digital tracking of exercise activities as a form of the accumulation of labour, which enables the extraction of surplus value. The transformation of exercise activities into digital data enables individual users to see their activities as a particular kind of “formative activity” through the representation of their achievements as digital data in the form of statistics or “medals”, which constitute a kind of objectification of the labour of the exerciser, which is relatively new to the amateur athlete. For corporations who are compiling these data, however, by transforming heterogeneous exercise activities into a standardized, quantified form, they are able to be made into a valuable resource; data that can be sold to advertisers. The exercise activities in which people engage are therefore seen as productive potential energy by corporations, who are likely to be using the design of hardware and software to subtly structure the behaviour of users to produce the kinds of data that will be of commercial value. Prior to the existence of easily available digital tracking technologies, there were few ways in which everyday exercise activities could be quantified and standardized in such a form that they are amenable to the accumulation and comparison of the data of large amounts of people. These developments are currently in their early stages, but may be indicative of not only a new form of surveillance, but an epistemological change in how exercise is understood, as well as signaling the potential commercialization of the exercising bodies of the population.

## **Acknowledgments**

I am grateful to Karen Throsby, whose comments helped me to improve this article considerably, but any mistakes or deficiencies are entirely my own. I am also indebted to the anonymous reviewers of this paper, whose constructive criticisms improved it immeasurably.

## **Conflicts of Interest**

The author declares no conflict of interest.

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# Apps as Artefacts: Towards a Critical Perspective on Mobile Health and Medical Apps

**Deborah Lupton**

**Abstract:** Although over 100,000 health and medical mobile apps have been placed on the market, few critical social analyses have been yet undertaken of the role of these apps in healthcare, preventive health and health promotion. In this article I present an argument for approaching the study of mobile apps as sociocultural artefacts, focusing specifically on those that have been developed on health and medical topics. This perspective acknowledges that apps are digital objects that are the products of human decision-making, underpinned by tacit assumptions, norms and discourses already circulating in the social and cultural contexts in which they are generated, marketed and used. First, I provide the context, by discussing the gradual digitisation of health and medical information since the advent of the Internet and the emergence of health and medical apps as one of the latest developments. Second, I discuss how a critical perspective may be employed to analyse the social, cultural and political dimensions of health and medical apps. Finally I illustrate how such an approach may be applied by giving a case study of an analysis of the top 10 ranked health and medical apps on the Apple App Store on one day, outlining some major themes and discourses that emerge.

Reprinted from *Societies*. Cite as: Lupton, D. Apps as Artefacts: Towards a Critical Perspective on Mobile Health and Medical Apps. *Societies* **2014**, *4*, 6066622.

## 1. Introduction

Mobile software applications (or “apps” as they are commonly known) have become an important element of contemporary digital technology use. Millions of apps designed for smartphones, computer tablets and other mobile devices have been published since their first appearance in 2008. Apple announced in mid-2014 that it had over 1.2 million in its App Store catalogue alone and that 75 billion apps had been downloaded by users. The other major app provider, the Google Play store, provides a similar number of apps to consumers [1]. Market research has found that mobile device users spend more time each year on using the apps they have downloaded. One survey of adult smartphone users in the USA found that the average number of hours respondents spent per month on using apps exceeded 30 hours, and that the respondents used an average of 26 apps each [2].

Despite this rapid expansion of a novel method of providing software programs to mobile device users, as yet very few critical social analyses of mobile apps have been published. In this article, as part of a developing research program in critical digital health studies [3–10], I focus attention on one genre of mobile apps: health and medical apps. The vast majority of research studies about this genre of apps have appeared in the medical or public health literature or market research reports. These studies take a primarily instrumental approach, seeking to review the effectiveness of apps or analyse the medical validity or safety of their content using descriptive content analyses. The wider

social, cultural and political roles played by health and medical apps as part of contemporary healthcare and public health practice and their contribution to notions of health, illness and embodiment have been little explored thus far.

In this article I seek to achieve three objectives. First, I provide the context, by discussing the gradual digitisation of health and medical information since the advent of the Internet and the emergence of health and medical apps as one of the latest developments. Second, I discuss how a critical perspective may be employed to analyse the social, cultural and political dimensions of health and medical apps. Finally I illustrate how such an approach may be applied by giving a case study of an analysis of the top 10 ranked health and medical apps on the Apple App Store on one day, outlining some major themes and discourses that emerge. In so doing I introduce the concept of the app as sociocultural artefact. This perspective acknowledges that apps are digital objects that are the products of human decision-making, underpinned by tacit assumptions, norms and discourses already circulating in the social and cultural contexts in which they are generated, marketed and used.

## **2. Digitising Health and Medical Information**

Health and medical apps are one of the newest developments in a trajectory of the digitising of health and medical information that has occurred over the past quarter century [5]. The emergence of the Internet and mass access to the World Wide Web in the mid-1990s (now often referred to as the “Web 1.0” stage) led to a proliferation of health and medical websites and online discussion groups offering open access to details about illnesses, diseases, health promotion and healthcare. These initial websites were mostly static, infrequently updating their information. They offered little opportunity for people to contribute details of their own experiences, although online discussion groups allowed for some interactions and sharing of information by patients and other interested users.

The digital technologies that have emerged in the past decade (now often referred to collectively as “Web 2.0”, or “the social web”) have expanded the opportunities for people to access and, in particular, share health and medical information with each other in digital forums. Patients and caregivers can write about their experiences, create and upload images or videos and rate healthcare providers and medical treatments using social media platforms and blogs and wireless mobile devices that can connect to the Internet from almost anywhere. In this age of digital “prosumption” (combining production and consumption of Internet content) [11], the ideal of the “digitally engaged patient” (otherwise referred to as the “e-patient”) has become dominant. This ideal represents digital technologies as offering patients and lay people the opportunity to ‘take control’ over their health via contributing to and harnessing online information and engaging in self-monitoring and self-care practices using digital technologies [6,12,13].

## **3. The Emergence of Health and Medical Apps**

Sociologists and other social researchers have yet to devote significant attention to the role played by health and medical apps as contributors to these digitised landscapes and ecologies. Yet

these apps have proliferated in recent years as part of a constellation of new digital health technologies that include telehealth and telemedicine, digital gaming technologies, digitised medical education and health promotion materials, wearable devices to monitor and measure bodily functions and activities, electronic patient records and booking systems and the use of large digital data sets (“big data”) to generate knowledge about healthcare, health behaviours and disease patterns (see [4,5] for an overview). Health and medical apps represent a major element of this market. Tens of thousands of medical and health-related apps for mobile digital devices have already been developed, and more are released onto the market each day. In mid-2014 there were over 100,000 health and medical apps listed in the two major app stores, Apple App Store and Google Play [14].

The health and medical apps that are currently available span a wide range of sophistication of content and markets to which they are designed to appeal. Many are very simple, providing information on a specific medical condition or treatments. Others involve highly detailed anatomical visualisations or incorporate complex algorithms to assist in calculating diagnoses, identifying risks or facilitating health and fitness self-tracking or patient self-care regimes. A variety of apps that are currently on the market are versions of medical training and education directed specifically at medical and other healthcare professionals and students. They provide detailed anatomical information and visuals, digital versions of medical textbooks and dictionaries, training videos and diagrams and drug prescribing information. Apps have been designed for the medical market that can monitor and measure many bodily functions and symptoms in patients as well as work with smartphones to conduct medical tests for diseases and conditions, including add-ons that act as mobile medical devices. Hundreds of apps have also been developed by hospitals and other healthcare providers to market their services and provide opportunities for patients to rate their experiences.

Many more apps are marketed to lay people to provide medical and health information or assist them in self-tracking of their bodily functions and activities. Others are directed at assisting patients to store and access their medical records and treatment regimens and track medical appointments, access medical trials, seek appropriate medical care, engage in patient support networks and share information on their condition with friends and family.

The Internet empires are entering the field of digital health. In mid-2014 Apple announced its new Health app that takes data on health and physical activities from third-party apps and consolidates them into a comprehensive health profile [15]. In September 2014 Apple also announced that its new smartwatch, the Apple Watch, would be released early the following year [16]. The Watch will have its own App Store devoted to new apps that are designed especially for its operating system. Among its other functions the Watch will act as a wearable health and fitness-tracking device. As well as allowing users to use third-party apps the Watch incorporates two new apps, simply entitled “Fitness” and “Workout, that will work with the embedded sensors to track users” physical activities and body metrics such as heart-rate [17].

*The Use of Health and Medical Apps*

Evidence suggests that health and medical apps are becoming increasingly used in a variety of contexts. Many writers in the medical and public health literature have drawn attention to the benefits that health and medical apps may offer lay people as well as healthcare practitioners [18–27]. While there is still little research on how people are using health and medical apps, in late 2012 a Pew Research Center survey found that 85 per cent of American adults owned a mobile phone. Fifty-three per cent of these were smartphones, and one fifth of smartphone users had used their phone to download a health-related app. The most popular of these apps were related to monitoring exercise, diet and weight [28]. A more recent market research study found that almost one-third of American smartphone users (equivalent to 46 million people) had used apps from the health and fitness category in January 2014 [29].

It would appear that healthcare practitioners and administrators are also increasingly using apps as part of their professional practice [23,24]. A growing number of medical schools are now offering at least part of their education via apps and require their students to own a tablet computer [30]. In one study that surveyed American doctors, more than two thirds said that they used apps as part of their work. Diagnosis apps were the second most-used category, following those for medication interactions [31]. Another survey of medical students and junior doctors in a UK healthcare region found that over half of both students and junior doctors had medical-related apps on smartphones, with apps for medical education purposes the most popular [32]. Commentators in the medical literature now often refer to “prescribing” apps to patients [33].

On the other hand, however, concern has been raised in the medical and public literature about the quality of apps and the validity of the medical information they contain. Any developer can publish a health or medical app, as long as they conform to the guidelines offered by the app store in which they are seeking to publish (Apple is far more restrictive of the content of the apps it offers than is Google [34]). As a consequence, health and medical apps vary wildly in the accuracy of their content and the extent to which they draw upon credible and reputable sources of information. Some app developers have longstanding reputations in online medical information and training resources and provide information about their medically-qualified editorial team. However many other app developers appear to draw on little or no direct medical expertise when generating the information they present on the apps they offer.

This issue has been recognised as a major concern in the medical literature. Several studies have been published that have identified significant problems with medical accuracy of apps’ content [20,35–37]. This research has found that many developers do not nominate specific medical experts in contributing to the content, or are vague in their attribution of authorship, using such terms as “doctors” or “a medical team” [38–42]. Other writers have sought to identify such issues as legal and regulation difficulties and conflict of interest in relation to medical and health apps [24,42–46]. As one commentator has observed, medical students are often presented with a list of apps that they are required to use with no discussion of whether or not the developers of these apps disclose conflict of interest. Yet there is nothing to stop a pharmaceutical company developing an app for the medical market that recommends its own products [46].



The relevant regulatory bodies in many countries have not yet established guidelines and regulations for overseeing medical apps. It has been contended that the content of all medical apps should be externally peer-reviewed by medical professionals to ensure quality and safety [35]. Regulatory bodies such as the US Food and Drug Administration (FDA) are struggling to establish the processes by which this should take place. In September 2013 the FDA issued draft guidelines for the regulation of health and medical apps [47]. Many apps in these categories do not come under these guidelines' purview, however, as what is considered a "medical device" is currently ambiguous, leading to confusion about exactly which types of apps should be submitted to the FDA for review [48]. Furthermore, these guidelines do not attempt to cover the vast numbers of apps that provide information on medical and health matters, meaning that consumers must exercise their own judgement concerning the validity and accuracy of this information.

#### **4. Critical Approaches to Health and Medical Apps**

The sociomaterial theoretical perspective on technologies has offered valuable insights into ways of thinking about the relationship between humans and nonhumans in the context of digital health. 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 [49]. This approach acknowledges the combination of the material and non-material, the human and the nonhuman, 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 [50]. Several sociologists have drawn upon the sociomaterial approach to theorise medical technologies [51–55]. They argue that via these technologies, specific meanings, concepts and practices are enacted in relation to health, disease, health care, public health, embodiment and selfhood. Medical technologies facilitate modes of knowing the body and disease [52].

Apps are one of the latest forms of medical technologies. From the sociomaterial perspective, mobile apps, like all technologies, are considered to assume certain kinds of capacities, desires and embodiments; they also construct and configure them. Apps may be conceptualised as the products of interplays between the human actors who make decisions about their form, content and use and the affordances offered by digital technologies which delimit the scope within which apps can be developed and used [34,56]. Apps are new digital technology tools, but they are also sociocultural products located within pre-established circuits of discourse and meaning. They are active participants that shape human bodies and selves as part of heterogeneous networks, creating new practices and knowledge. They are therefore generative, a productive form of power [57,58]. Apps may further serve political purposes by championing or supporting vested interests and established forms of dominance and authority.

The technical affordances of apps structure the ways in which they are used and the meanings that are ascribed to them. The mobility, ease of access and use of apps is a particular feature that differentiates them from earlier sources of health and medical information. Due to their simple format and location on mobile wireless devices, apps can be easily downloaded and carried around

for constant reference or updating the user's own information or comments and sharing these with others. The well-known motto of Apple—"There's an app for that"—suggests the multi-functional dimensions of apps. Many apps are free or obtainable for a small charge, and they are easily and quickly downloaded (and just as easily removed from a device). Another distinguishing feature is the function of many health and medical apps that connect them to sensor technologies in smartphones or wearable devices that promote detailed and continuous monitoring of bodily functions and behaviours. Unlike older-style websites, such apps are able to facilitate the generation of constant digital data on the user's body that can then be transmitted in real-time to healthcare providers or carers or friends and followers on social media sites.

Apps also provide far more opportunities for lay people to access medical information that was previously only available to healthcare practitioners or students, confined to medical libraries, health and medical training and education course materials or professional associations. While many medical apps are designed expressly for the healthcare practitioner and student audiences, they are freely available for any others to download and consult. Indeed many apps have been developed expressly by medical and public health authorities for the purpose of informing members of the public about medical and health issues, such as infant care, immunisation, weight loss, smoking cessation and many more [3,4,8,9]. Whether providing medical information or ways for people to promote their health, apps contribute to public pedagogies on health and medical matters [59]. A further important difference between health and medical apps and previous online technologies is the issues they raise for the security and privacy of the often very personal information that some of these apps generate about their users, given that these data are often uploaded to the developers' platforms supported by cloud computing.

All of these features and affordances of health and medical apps require critical attention and theorising. As sociocultural artefacts and actors in social networks, the content and use of health and medical apps can tell us much about which types of illnesses and health conditions are considered important at a particular moment and what medical or health promotion strategies are privileged to prevent or treat these conditions. Various types of capabilities and responsibilities are produced via medical and health apps. They have significant implications for the practice of medicine, medical authority, the delivery of healthcare and public health work and the doctor-patient relationship. These apps have the potential to shape the ways in which the human body is understood, visualised and treated by healthcare workers and non-professional people alike.

In several recent studies I have conducted on health and medical apps, I have adopted a critical approach to the analysis of these technologies. For example my study of sexuality and reproduction apps designed for people to use for self-tracking and monitoring purposes found that concepts of reproductive and sexual embodiment as they were represented in the apps were strongly gendered, supporting norms and assumptions about male and female sexual and reproductive bodies. Male sexuality was rendered as ideally high-performing and competitive, unrelated to reproduction. In contrast, few apps were designed for women to rank their sexual performance. However nearly all reproduction apps were targeted at women, centred on their health and fertility [7]. Another of my current studies that focuses on pregnancy apps identifies the focus on self-responsibilisation via self-monitoring of one's own body and that of the unborn that is evident in the apps' focus. These

apps seek to enrol pregnant women by highlighting the ways in which close self-monitoring of their pregnant bodies may avoid posing risks to their unborn as part of a broader ethos of reproductive citizenship that involves many other forms of information and digital devices. Pregnancy apps, however, offer even greater opportunities for women to engage in obsessive self-surveillance because of their capacity to produce detailed data continuously in real-time (including using sensors to monitor the pregnant and unborn bodies, such as maternal and foetal heart-rate) and the function many offer of sharing these data with others on social media networks. Here again gendered norms as well as expectations about “good motherhood” are reproduced in such apps (see also [60]).

### **5. Case Study: Top-Ranked Health and Medical Apps in the Apple App Store**

To provide a further example of how social researchers might approach the critical analysis of apps as sociocultural artefacts, I present some analysis of the first 10 health and medical apps that were listed in the charts of most popular apps as they were published on the Apple App Store on a day in September 2014. This involved a total of 40 apps, including both the paid and free apps for both categories, as these are separate lists. The App Store was chosen for this purpose because it is one of the two major providers of apps (with Google Play) and because its daily top app charts provide an easily accessible overview of the currently popular apps by content category. The Apple App Store categorises apps into either the “Health & Fitness” or the “Medical Category” based on the app developers’ nominations of which category their apps are designed for. The top charts are reconfigured each day in response to users’ downloading habits. As such, the apps listed in this analysis provide only a “snap-shot” of a particular moment in the top 10 (although some apps may stay in the top 10 lists for several weeks or months if they are very popular).

I examine some of the aspects of app content that may be investigated, including topics, approaches, appeals to authority, use of text and imagery and details provided about the developer. App topics can suggest trends in health and medical regimes, treatments and conditions as well as methods in medical education and training. The ways in which they verbally and visually represent the human body provide insights into contemporary notions of embodiment, health and disease. Examining the words used in the app titles and descriptions on the stores and the images used, including the logo and screenshots employed to illustrate what the app offers potential users, is a way of identifying the tacit assumptions that underpin them and their truth and authority claims. Clicking through to the developers’ websites to examine their credentials and the statements that they give about privacy of the data that may be uploaded to their platforms and the terms and conditions of use provides another important source of information concerning the knowledge economy of apps and the digital data that they may generate.

Table 1 provides a list of each app appearing on the top 10 for each of the top charts that were examined.

**Table 1.** List of top 10 health and fitness and medical apps on the Apple App Store.

<b>Health &amp; Fitness (paid)</b>	<b>Health &amp; Fitness (free)</b>	<b>Medical (paid)</b>	<b>Medical (free)</b>
7 Minute Workout	Personal Workout	Essential Anatomy 4	Gray's Anatomy Student
Body Trainer	Daily Ab Workout	Muscle System Pro III	Breathing Zone Free— Relaxing Breathing Exercises
Healthier—Break Reminder	Relax Melodies	3D Human Body Organs Reference	Essential Skeleton 4
Weight N Watch—Daily Weight Tracker	Sleep Pillow	Anatomy Quiz+	Biology and Human Body Anatomy
Break Reminder	White Noise Lite	Pocket Anatomy	Relax with Benjamin DeFoor —Sleep & Hypnosis
Eye Break	Relax Melodies Seasons	Gray's Anatomy Premium Edition	MRICro Viewer
Easy Calorie Counter	Music Healing	iMedicalOffice	Plastic Surgery
Simply Being—Mediation for Relaxation & Presence	Paleo Diet Recipes	Learning USMLE	iSurf Brainview Desktop
Brainwave Tuner	FreeBMI	DiabetesPal	MBBS Year II by WAGmob
All-in Yoga	Lose Weight with Benjamin DeFoor	Blood Pressure Diary	Living Lung—Lung Viewer

As shown in the table, the top 10 paid apps in the health and fitness category in the Apple App Store were those directed at working out (“7 Minute Workout”, “Body Trainer”), counting calories (Easy Calorie Counter) and controlling body weight (“Weight N Watch—Daily Weight Tracker”), reminding users not to sit for too long at a computer and to exercise their bodies and eyes (“Healthier: Break Reminder”, “Eye Break” and “Break Reminder”), meditation and relaxation (“Simply Being—Mediation for Relaxation & Presence”, “Brainwave Tuner”) and yoga (“All-in Yoga”). The top 10 free health and fitness apps again focused on workouts (“Personal Workout” and “Daily Ab Workout”), relaxation and better sleep (“Relax Melodies”, “Sleep Pillow”, “White Noise Lite”, “Relax Melodies Seasons”, “Music Healing”), diet (“Paleo Diet Recipes”) and weight loss (“FreeBMI” and “Lose Weight with Benjamin DeFoor”).

The list of the top 10 paid medical apps was dominated by human anatomy apps. Six of the top 10 paid apps included detailed anatomical atlases of the human body (“Essential Anatomy 4”, “Muscle System Pro III”, “3D Human Body Organs Reference”, “Anatomy Quiz+”, “Pocket Anatomy”, “Gray’s Anatomy Premium Edition”). It was evident from the wealth of detail provided in these apps on human anatomy, including images of muscular and skeletal systems and the like, as well as the titles and text of the app descriptions and developers’ websites, that these apps were predominantly directed at healthcare practitioners and students rather than lay people. The “iMedicalOffice”, an app for electronic health records software, was also designed for healthcare practitioners and institutions, while the “Learning USMLE” was a training app for American medical students seeking to take the medical licensing examination required for practising medicine in that country. However the two remaining apps in the top 10 paid medical app category were designed for patients to monitor and self-manage two chronic health conditions: diabetes (“DiabetesPal”) and high blood pressure (“Blood Pressure Diary”). The “Diabetes Pal” app

encourages people with diabetes to record their detailed bodily data on the app software and these data are automatically synced to the iCloud. The “Blood Pressure Diary” app also involves users self-monitoring and uploading their bodily data to the app.

The top 10 free medical apps on the Apple App Store were also predominantly directed at medical or healthcare professionals (seven of the 10). There were four human anatomy apps similar to those appearing in the paid medical app chart. Two of the top 10 medical apps were related to medical images. One was for viewing images such as MRIs and CT/CAT scans (“MRIcro Viewer”) and the other was designed as a tutor for medical education in brain MRI and neuroanatomy (“iSurf Brainview Desktop”). The list also included the “MBBS Year II by WAGmob” app that the app description nominates as helping second year medical students understand the basics of pharmacology, pharmacy, medicinal chemistry, pathology, genetics and genetic engineering using such techniques as tutorials, quizzes and flashcards. For a more general audience, the chart included a breathing control and relaxation app (“Breathing Zone Free—Relaxing Breathing Exercises”) and another app for relaxation featuring self-hypnosis (“Relax with Benjamin DeFoor—Sleep & Hypnosis”), as well as an app (in Spanish) designed as a support for patients who were contemplating or had undergone plastic surgery (“PlasticSurgery”).

A constellation of interesting social, cultural and political elements may be discerned from this sample of health and medical apps. These include digital bio-objects; healthism and individualism; claims to authority and commercial interests; and data privacy and security. These are further discussed below.

### *5.1. Digital Bio-Objects*

Many of the apps described above engage in visual representations and other forms of providing information on the human body. In the case of the human anatomy and body scan reading apps designed for medical practitioners and students, these representations are highly detailed, producing in-depth digitised atlases of the body that render the body transparent to the gaze by peering at what lies beneath the skin. Self-monitoring apps designed for the use of lay people as part of preventive health or the management of chronic conditions participate in a different form of gaze. As was evident in the apps directed at patients engaging in self-care for diabetes and high blood pressure, many apps encourage users to monitor their bodies closely, generating data on many bodily functions.

Webster [54] uses the term “bio-objects” to describe the assemblages created by new biotechnologies. We might productively view the assemblage that is configured via the interactions of human bodies and apps as a digital bio-object, as are the digital data that this assemblage produces. These digital data assemblages, which have also been referred to as “data doubles” [8,61,62], comprise new forms of patienthood and embodiment when configured via apps. They make visible dimensions of the body that previously were hidden, and expose them to often vast audiences by generating digital quantifiable data about bodily functions and behaviours [8].

Not only, therefore, are traditional forms of representation of the human body used in health and medical apps (such as the anatomical images that feature in the medical apps) but also new forms of digitised embodiment, as are generated using self-monitoring health and medical apps. Unlike

the static images of the body used in the human anatomy apps, the data doubles that are thus produced by individuals using these apps are constantly changing assemblages as new data are fed into them. These data doubles are representations of the user's own body created by use of the app. The information that they configure on the user serves to shape future actions, thus creating a cybernetic relationship between data double and user [8,9,62]. These data have a liveliness and vitality, a social life of their own [50,63,64] that is facilitated by the app.

## *5.2. Healthism and Individualism*

Technologies such as health and medical apps represent the vagaries of human embodiment as amenable to control if sufficient vigilance and self-responsibility are exercised. When behaviours and body functions are digitised as quantifiable data, indicators and concepts of health and fitness become narrow representations of these phenomena. Health and wellbeing become represented by certain numbers that are collected by one's self-tracking device, game app or sensor-embedded smart object [3,7–9,59,62].

The health and fitness concerns addressed by these apps demonstrate that efforts to train one's body, lose weight, avoid sitting for too long but also accomplishing work productivity and achieve relaxation and better sleep are important for many of those who download both paid and free apps. Returning to the top 10 paid health and fitness apps, for example, the "Healthier: Break Reminder" app has the tagline "Work Healthier, rest smartly". The description notes that "Research has shown that prolonged sitting in front of a computer not only damages health, but also decreases productivity. Healthier helps you to tackle both." The app description ends with the call to "Start getting healthier today!" The logo features a silver shield with a stylised red love heart shape inside it, suggesting that the app will protect heart health. The description of the app notes that it periodically reminds the user to take a break from their computer as well as providing "HealthierTips" involving "office-suitable exercises for both eyes and body" in which users can engage when taking a break from sitting at the computer. This app, therefore, supports the notion of the healthy worker as productive worker.

Apps that are directed at influencing health-related behaviours and encouraging patient self-care and voluntary promotion of one's own health may be viewed as contributing to a neoliberal political orientation in which "healthism", or the privileging of health above other priorities [65,66] and taking responsibility for one's own health [8,9,67] are idealised. Such perspectives on health and illness states routinely fail to acknowledge the social determinants of health in their focus on individuals and their management of their health. Digital technologies such as health and medical apps tend to support these individualistic approaches [3,5,7–9,12,59,62]. While some apps may feature the opportunity to people to engage with a community of like-minded individuals who are attempting to achieve the same ends, very few are directed at broader social change or activist politics in the spirit of the new public health [3,4].

Furthermore, the taking up of self-tracking health apps and devices in an ever-growing variety of social domains has led to people being "pushed" or coerced into using such technologies in the interests of other actors and agencies. Health and life insurers are beginning to encourage their customers to use self-tracking devices and apps to collect personal health and fitness data and

upload these data to their platforms in the interests of gaining “rewards” or being offered lower premiums. Such uses of apps and the personal data they generate raise pressing questions about potential social and economic discrimination against people who do not wish to participate in these activities or those who are identified as not meeting targets for appropriate body weight, good health or physical activity levels [64]. Algorithmic calculations using personal health data may lead to predictive privacy harms [68], where individuals are singled out as being “at risk” from ill health and therefore forced to pay higher insurance premiums or may be refused insurance, credit or employment [69].

### *5.3. Claims to Authority and Commercial Interests*

The types of authority that are presented in health and medical apps and their roles as agents in the knowledge economy also require attention. As several writers in the medical and public health literature reviewed above have pointed out, many app descriptions or developer websites fail to acknowledge how the specialised health or medical information that are presented in the apps are generated. The apps assume an authority on health and medical matters that are not always supported by any provided material as evidence of how the content was derived, whether it is regularly updated and so on.

This lack of information was evident in most of the apps I analysed above. The developer of the top-ranked paid medical app, “Essential Anatomy 4”, for example, is the 3D4Medical technology company. On its website the company notes that it “specializes in the development of medical, education and health & fitness apps for professional reference as well as student and patient education”. It is also claimed on the website that the company has achieved over 10 million app downloads worldwide, and is clearly successful in marketing its apps. However the company does not provide much detail about how its medical information is derived, noting only that its apps “have all been medically approved and designed to the highest standard”. The developer of the app directed at educating second year medical students, WAGMobile, is a generalist app development company that provide apps for clients in numerous categories. It does not provide any details of how the content is generated, and indeed offers a disclaimer at the bottom of the app description that notes “Please do not take any action based on the content of this app”; an odd caution given that the material is marketed at accomplishing training for medical students.

Apps contribute to a political environment in which the Internet empires are increasingly exerting a variety of “soft power” in their dominance of the digital knowledge economy [50,70,71]. In the age of big data, the data that are generated by apps are becoming increasingly commercialised. As part of engaging in these acts of presumption, users’ personal data are exploited and transformed into commercial profit by other actors and agencies [10,72]. The data produced from self-tracking apps and devices, patient support and opinion websites and those scraped from social media sites where medical and health topics are discussed, for example, possess great value to pharmaceutical, healthcare and biotechnical companies as well as government agencies and public health enterprises [10]. However it is not always apparent where vested interests lie in the provision of medical information in apps either for lay people or members of the medical profession [10,46,73]. At present there is no way of fully identifying the role that

pharmaceutical companies or medical device developers may have played in contributing to the content of apps.

#### *5.4. Data Privacy and Security*

The lack of information that is provided in many app descriptions or on the developers' websites means that there is often very little transparency about how users' personal information is used by the developer or other parties to which these data may be sold. This was evident in the self-monitoring of chronic diseases apps that featured in the top 10 paid medical app list. The company that the "Diabetes Pal" app, Lobotomo Software, provides no information on the app description or its website on their privacy policy or terms and conditions of use of the app, despite the fact that the app is collecting several aspects of personal health data and storing these data on a cloud storage platform. This is also the case for the "Blood Pressure Diary" app.

In the wake of the Snowden revelations about the use of app data and other personal digital data use in national security surveillance operations, more attention has been paid to data security and privacy on digital platforms and devices. The extent to which the personal health and medical data information that is collected by apps are used commercially and on-sold to third parties is becoming revealed [74–76]. Several reports recently published by privacy organisations have noted the lack of details offered by many medical and health app developers of what they do with users' personal data [73]. The Global Privacy Enforcement Network in a sweep of over 1000 apps found that 60 per cent raised privacy concerns. Many failed to properly inform users how their personal data were being used or made excessive demands for personal data from users [77].

It appears that developers are beginning to take note of consumers' growing concerns about data privacy and security. A market research report of a survey of more than 2000 health and medical app developers found that data security and standards issues were viewed as barriers to further development of this app market [14]. It is notable that in its latest health and medical-related technologies Apple is taking steps to protect users' privacy by outlining how technology developers may use their HealthKit framework in their App Store guidelines. These note that users are given control over their data by explicitly granting each app permission to read and write data to the HealthKit store. The HealthKit data cannot be saved to iCloud or synced across multiple devices and are kept only on the user's device. App developers are not permitted to use information gained from their apps for targeting users with advertising or similar services or disclose users' data to a third party without express permission from the user. Even if permission is granted, the app developers cannot share information with a third party unless they are also providing a health and fitness service to the user, and app developers cannot sell users' data to third parties. App developers are required to state clearly how they will use their personal data and provide a privacy policy. Apps that provide diagnoses, treatment advice or control hardware designed to diagnose or treat medical conditions that do not provide evidence of regulatory approval will be rejected [78].



## 6. Conclusions

In this article I have begun to outline an agenda for understanding and analysing health and medical apps as sociocultural artefacts that are actors in heterogeneous networks of other actors, both human and nonhuman. By presenting a case study of how a critical social analysis of health and medical apps may be undertaken, the kinds of features evident in such technologies' representations on app stores have been identified. Such a brief analysis, however, can only go so far in fully illustrating the symbolic and social nature of health and medical apps. I have only touched on a tiny proportion of the vast array of topics and practices that health and medical apps cover.

Much more research is required from a critical perspective on these technologies. Few in depth studies have as yet been conducted into the ways in which lay people engage with health and medical apps, including non-users or those who take up some apps but then relinquish them shortly afterwards. We know very few details about how health professionals such as medical practitioners, hospital administrators, public health professionals and health promoters are incorporating apps and associated mobile digital technologies into their work practices. Little knowledge is available on the practices and tacit assumptions of app developers and designers and the companies that commission apps. Nor do we know how lay people and healthcare and public health workers might be resisting or subverting these devices or creating their own. Analysis of the circulations, transformations and repurposing of the digital data that are generated by apps requires further attention, as do the topics of personal data security and privacy as the domains in which personal health and medical data are collected and used expand. Detailed social research that is able to elucidate the situated knowledges, meanings and uses of apps offers immense potential for social researchers who are interested in health and medicine and in digital technologies.

## Conflicts of Interest

The author declares no conflict of interest.

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