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HOUSEHOLD SELF-TRACKING DURING A GLOBAL HEALTH CRISIS

Shaping Bodies, Lives, Health and Illness

DR. MARIANN HARDEY

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BY

DR. MARIANN HARDEY
University of Durham, UK

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INVESTOR IN PEOPLE

This book is dedicated to Penelope Cat who spent many hours sat on the keyboard and self-tracking.

CONTENTS

ABOUT THE AUTHOR

Mariann Hardey is an Associate Professor of Business and Computing at Durham University Business School and a member of the Directorate for Advanced Research Computing (ARC) at the University of Durham, where she teaches business inclusivity, self-help, and business technology. Mariann is interested in self-development and learning, with a particular emphasis on representation among business leaders and practitioners. She has given numerous presentations at international conferences and events, including the United Kingdom's first TEDx, and her work has been featured in international media. Mariann received an ESRC scholarship to study at the University of York and the University of Sussex, where she earned degrees in English Literature in the School of American Studies, a Masters in Women's Studies, and a Doctorate in Sociology. Her most recent book, *The Culture of Women in Tech: An Unsuitable Job for a Woman*, delves into the 'problem' of women in the technology industry.

FOREWORD

3, 477 steps to the local newsagents for a Beano comic and another six steps to the bakery next door for a large sticky bun.

From the age of eight, I had been using a pedometer to count the steps from home to school, to my favourite sweet shop, to a friends' home, to bed, and the number of paces to the den in the back garden of our 1930s council house in Surrey. The pedometer was part of a research project my father was helping to put together about health in the home. It was both a connection to him and a fascinating tool of wonder for me. The simplicity of counting steps became a game for me and I took it everywhere. Today, the formula of 10,000 daily steps is marketed to consumers of health technologies as equating to personal improvements in health, such as helping to prevent or alert heart failure, protecting mental health, and lowering diabetes risk.

Self-tracking has a broad remit and will play an essential role in understanding health change and responsibility in the future. It is concerned with the application of social, business, and human-computer theories and models in the promotion, commercialisation, and maintenance of health and the individualised and interpersonal aspects of adaptive behaviour among those with ill health.

From the perspective of a social scientist, *Household Self-Tracking During a Global Health Crisis* examines contextual, personal and social factors surrounding health tracking, including the commercialisation of Covid-19 health tracking, public data tracking, and health surveillance issues. Alongside the global pandemic, other crises are evident concerning, for example, food sustainability, coping with chronic health conditions, the demands of caring roles, and mental health and well-being.

The book's premise is to capture different types of health tracking within households to understand better the extent to which tracking practices are being shared. In focusing on this, I have set tracking in the context of domestic use and its broader social, political and consumer contexts. Through interviews with 36 diverse global households, the book analyses how such trackers exhibited a persistent interest in health data and how behaviour was affected within families who, like mine, were tracking throughout the pandemic.

Inequalities in health are highlighted, as are extended conceptions of fitness and illness management, as part of a substantial shift in comprehending and integrating health regimes in the home. Some of the more contentious aspects of self-tracking, such as worries about data bias in health biometric data, are addressed. The book also responds to the sense of global health identity by offering a critical account of these developments and situating them in relation to the long-term neoliberal health agenda.

I contend that neglecting the effects of household factors on health or focusing exclusively on individual tracking behaviour is no longer an option in understanding contemporary health practices. We know a lot about individual self-tracking experiences, but much less about how households reframe or redefine health and illness using self-tracking technologies together. One aim is to synthesise and extend analyses of the social construction of health – including being fit and avoiding illness. This book will assist researchers interested in investigating self-tracking and health technologies, as well as postgraduate students studying psychology, medicine, social science, and business, and undergraduates studying in fields into which health surveillance studies have been incorporated, such as sociology, business studies, and human-computer interaction (HCI) studies.

Some of the insights are personal, and some of the material from which I draw may be unfamiliar to some social scientists. However, I argue that understanding the personal and social dimensions of tracking within households, particularly during a significant global crisis, will enrich our understanding of health consumption and knowledge.

The discussions in this book offer much concerning household's response to health crises and reveal much about the experiences of managing health through a range of sometimes quite sophisticated self-tracking technologies. One of the book's unique contributions is that it captures people in households with varied health tracking experience: some are very confident and deeply embedded trackers, and others who are entirely new to tracking. The mixed level of use of tracking technology in these households highlights the importance of examining and comparing different individual and collective experiences of self-tracking, which has been largely overlooked in the current literature. However, it should be apparent that the findings here are limited to the trackers, the privileged few who have access to and can afford to invest in tracking technologies.

Finally, it should be apparent that I am a tracker, and I utilise my own experience of health transformation in tracking to illustrate processes of reframing and redefining health during a period of global crisis.

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INTRODUCTION: SELF-TRACKING CONSTRUCTION OF HEALTH

The commercialisation of health promotion through self-tracking technologies is symptomatic of a larger social and cultural health change characterised by increased investment in and image construction of fit and healthy living.

Our sense of self, identity and way of being and interacting with the world around us are all influenced by our health. Health is an integral part of how we can express ourselves and our experiences as embodied subjects. Health can motivate us, subdue us, provide expressions of pleasure or pain and help us understand the relationships and situations in which we find ourselves. This chapter focuses on the social construction of health in the context of health technologies which allow users to enact various forms of being healthy.

The chapter begins by explaining the global health context and how people perceive health crises, and in this regard, how the most privileged nations' global governance of health and disease is linked to that of the most impoverished. Such power structures, I argue, operate directly through a neoliberal global health agenda. Next, we consider the consumer environment of health technologies and delve into the history of the quantified-self movement. The consumer focus is to demonstrate how tracking is influenced by market forces promoting a sense of health in crisis and personalised responsibility for risky behaviour (McFall, 2019). As we move through the chapter, I explain how the marketing and consumption of health apps are purposefully linked to sociality, with health data tracking serving as a physical and immaterial location for larger structures designed to confront users with how they decide to make health choices. The core theoretical context is the construction of health as it relates to health promotion and personalised health practices made possible by tracking technologies.

GLOBAL HEALTH AND GLOBAL CRISES FROM CURE TO PREVENTION

Each person's perception of health and experience of illness is unique, shaped by their background and social circumstances. But the emphasis on individualised and private health practices tends to obscure the impact of collective issues such as extreme poverty, climate change, class, race and gender. In seeking to understand the context of self-tracking, it is important to establish the shift toward a global framework to manage health. Global insight pathways into disease control and health inequity are crucial for health promotion and have shifted the focus of political decision-makers away from individual and towards collective responsibility (Krumeich & Meershoek, 2014). Here, there is an acknowledgement that the progressive integration of national economies and societies into a global economy has influenced mainstream health, policy, thinking and attitudes and plays a critical role in how we respond to health crises (Schrecker, 2016, p. 4). Indeed, the impact of globalisation has been convincingly demonstrated, with authors pointing to new patterns of health consumption, competition and spatial compression (see, Dodgson, Lee, & Drager, 2017). Such factors influence various response efforts, as well as preparedness in terms of the legitimacy of government-centric conceptions of health crises and responses to global health emergencies, and policies within global health initiatives have yet to address this. Against the backdrop of recent escalating demands for access to healthcare and the political imperative to coordinate health education and preventative programmes to address health inequalities health promotion has shifted to a focus on collective responsibility rather than individuals or at-risk groups. According to Van den Broucke:

> *Enabling people to increase control over their health and its determinants is at the core of health promotion. As such, health promotion may paradoxically be more important in this time of crisis than ever before.*
>
> *(Van den Broucke, 2020 para. 3)*

The widespread perception of a 'global health' context and how it might be governed reveals a new mix of power and ideas, agency and structure, that influences approaches to health, individual responsibility, and identity. (Rushton & Williams, 2012). Rushton and Williams view the global health context as the product of various 'material and ideational drivers', where the:

> *[…] reshaping of the governance architecture has coincided with an unprecedented 'resource boom' in global health, and the emergence of health as a matter of 'high politics'. These developments might*

> *have been expected to improve responses to global health problems. Yet it is widely accepted that the failure to generate adequate responses to manifest health needs, particularly the needs of the poor, persists.*
>
> *(Rushton & Williams, 2012, p. 148)*

Taking up Rushton and Williams' observation of high politics in health strategies, the current global pandemic has further underscored global health disparities in which the needs of the poorest have been overlooked or completely ignored. This framing emphasises the rapidly changing global health environment, as Sendell observes, which is infused 'with evolving social consciousness and implied social decrees on a stage of neoliberal ideologies, bureaucratic inaction and political rhetoric' (2021 para. 1). Global health governance is strongly linked to neoliberal initiatives in public health policy, lifestyle, consumption, risk and health practices. The core message is that individuals are ultimately responsible for adopting any new behaviours in response to the juxtaposition of global health promotion with local contexts. As a result, there is a greater emphasis on individual agency, which aids the modern health-conscious movement and construct of citizenship (Ayo, 2012; Maravelias, 2018). For instance, the voluntary self-monitoring and quantification of sexual and reproductive health activities allow users to track fertility, monitor their sexual health, manage pregnancy and create new practices and knowledge about sexual behaviours (Lupton, 2015b; Sohda, Suzuki, & Igari, 2017). People are expected to maintain and monitor their health due to a critical shift from cure to prevention, as expressed in health promotion information and public health policies. Self-tracking, therefore, is promoted as a means to self-improvement, with an added message of collective social responsibility concerning how an individual might need to access public health services. In a broader sense, this reflects the top-down structural determination of tracking, where individuals are responsible for adapting or conforming to various health behaviour patterns. While as a user of tracking technologies one may find such personalised, tailored health information persuasive (and exciting), one also has to consider the long-term immersion within big data architectures and the way individual performance is measured against the performance of other users. Such issues are critical to how we frame future health choices when we consider the global organisation and ownership of tracking health data and their major implications for social discrimination and exclusion issues (Fotopoulou, 2018; Lupton, 2016a).

Sharon (2017) have written extensively about how values enacted in self-tracking practice allow individuals to be more involved in their health management. She makes a case for such data to form part of clinical decision-making, and states that personalised health information 'should enable individuals to become more informed, more engaged, and more in control of their health' (2017, p. 97). The framing of health responsibility is significant here. One perspective is that tracking allows the individual to control how their health is treated and changes how they might go through a diagnosis process. However, the current design of health tracking technologies means it is difficult for users to understand where their data are being shared and stored and what kinds of information might be monitored by third parties. Bithaj Ajana's observes a sense of users '"resignation" in the face of what is perceived as all-encompassing and ubiquitous data use' (2020, p. 654). To return to the framing of health responsibility, lawful users – whom Ajana refers to as 'innocent' – and who have nothing to hide, frame health data in such a way that makes it seem unproblematic, when it is precisely the opposite. In this regard, we should be concerned about health data sharing and the overt push to trust health data companies, when they are primarily commercial operations designed to compete in a very competitive health sector based on technological innovations. Trust is a key component of discussions in chapters One, Two and Three, where I consider how new data collection and personal information-gathering practices are changing how people understand personal and social responsibility for health.

Where questions around data privacy have been raised, the commercial and marketing side of self-tracking technologies have benefitted from the 'health is wealth' message and sense of a global health initiative. In parallel, there is also a growing social cachet to successfully achieving a 'fit body' and a growing prejudice aimed at those who do not correspond to an ideal fitness type. Self-tracking does much to perpetuate the ideal image of fitness, and a considerable amount of social research has demonstrated bias against those considered unfit or who do not conform to expected norms. Giese and Ruin summarise such a critique:

> *People whose bodies do not conform to these ideals – possibly as a result of their own free choice but also due to a particular physical disposition – are at risk of being excluded to some extent because they do not conform with the normative expectations of society. Against the trend of physical self-optimisation, their bodies are in danger of being forgotten [...] They are denied the status of being fully human.*
>
> *(2018, p. 152)*

Both health and bodies are now highly quantifiable. One issue for the consumer is that the forms of quantification are frequently contradictory and do not easily allow trackers to understand health conditions or achieve health goals. Forms of quantification are characterised by real-time, convenient and immediate datafication (e.g. weight or step tracking), in line with the commercialisation of health technologies. Achieving health goals is characterised by aestheticization, denial and long-term goals, in line with the emphasis on progress and effort to achieve a particular look. Health tracking has, therefore, become a focal point for how people understand and respond to global and social structures. This is evident in the meanings associated with the term 'healthy', as well as the commitment to health goals and the types of health activities undertaken as part of a global society. It is clear that the promotion of a health app does not eliminate global health or social inequalities. More broadly, the commercialisation of health promotion through self-tracking technologies is symptomatic of a larger social and cultural health change characterised by increased investment in and image construction of fit and healthy living.

It is evident self-tracking presents an individualised model of health regimes designed to encourage active engagement in health and access to services. An apparent tension is that while individuals are encouraged to invest in personalised health regimes, at the same time, such regimes are managed by wealthy global tech corporations. The risk with health tracking is when personal data entered into tracking apps, even those paid for by users, are not protected by privacy legislation, or any form of patient charter. Self-tracking devices are often associated with self-surveillance, and recent studies show that users' reluctance to trust app operators and concerns about their participation are often linked to data privacy (Becker, 2018; Oravec, 2020). Commercial companies operate outside of health data legislation, making it difficult for users to fully understand the protocols for collecting and sharing potentially sensitive information. A good example of this kind of tension is the upsurge in menstruation tracking, inviting women to record intimate details about their bodies. Such personalised data could be used to understand women's health – cataloguing symptoms, helping to work out different responses to disease and the effect of medicines. Such opportunities align with, for example, WHO's sexual and reproductive health initiative for access to safe, effective and affordable healthcare services ('Sexual and reproductive health', 2021). But in 2019, for example, Privacy International, a non-profit organisation based in the United Kingdom, investigated several popular period-tracking apps and discovered that two of them shared details on users' symptoms and contraceptive use with Facebook and other companies (Gupta & Singer, 2021).

The convergence of the global health context and individual adoption of self-tracking technologies represents a complex set of intersecting issues that has resulted in a muddle of competing interests, risk and ownership. On the one hand, self-tracking represents a near-ideal set of practices in which the individual can tap into new resources emphasising autonomy and empowerment while also contributing to new global frameworks for understanding health and engaging with health policy programmes. On the other hand, self-tracking represents a movement tightly bound to commercial tensions while at the same time attempting to reconcile the requirements of different users. At the heart of these multiple sources of influence and engagement, the emergence of a formal self-tracking movement and related communities has established new daily health practices as legitimate targets and goal-setting criteria for health. It is to such commercial tensions and goal-setting that we now turn.

COMMERCIAL TENSIONS AND THE QUANTIFIED SELF

Health trackers will be familiar with the target of 10,000 steps a day, designed to increase physical activity, which is set up as one of the automatic health goals in most tracking apps (see the Preface for my narrative about beginning self-tracking by counting steps). The automatic collection of vast amounts of personal data, such as daily steps, information about illnesses and chronic health conditions, and, increasingly, fitness image data based on body composition, forms the backbone of tracking culture and is marketed as appropriate goal-setting for health promotion. Alongside automation, patients and healthcare workers are seeking alternatives to face-to-face contact when they are unable to physically access health professionals. In Sweden, Joint Academic is a smartphone app and licensed physiotherapy provider. According to a BBC News report, the app generates revenue by charging regional healthcare authorities to enrol patients in digital physiotherapy programmes (Savage, 2021). As part of the business model, private health insurance companies refer some patients to the app to keep track of patient progress and monitor data as part of future policy claims. Both automation and at-distance or in-home healthcare solutions reflect a recognition of the health consumer and how personal fitness can be commercialised as part of a more comprehensive approach to health. Through medical tracking programmes, both self-tracking and clinical data measurement represent a significant social and cultural shift in individual health responsibility. At the same time, there is a correlation between the design of the user experience for practitioners and for consumer markets in the ways each seeks to capture data. According to the Pew Research Centre's report *Hopes About Life* in 2025, the majority will accept detailed health tracking as a 'valuable public good' (Anderson, Raine, & Vogels, 2021). In this context, there is a reinvention of 'health care and education to improve service and reduce costs as we learn the lessons from several COVID-19 waves' (Padbury, Anderson, Rainie, & Vogels, 2021). This recognition of change in the way healthcare decisions are made suggests that medical and healthcare teams and commercial organisations are keen to combine new clinical and commercial opportunities with self-tracking. The idea of self-tracking being used to support data-driven medicine and opportunities for digital connection between patients and care providers is becoming more common. This raises concerns about where data will be stored and processed, who will have access to it, what the legacy of such data will be, and what clinical and medical value will be derived from it. Users who are looking for seamless connections between personal health data goals and clinical treatment plans will quickly lose interest in self-tracking if it is designed to simply push notifications about commercial health targets.

While some research indicates the health benefits of 10,000 daily steps (e.g. increased awareness of daily physical activity, and improved heart health, mental health and lower diabetes risk (Hallam, Bilsborough, & de Courten, 2018)), the origin of the target is an excellent example of a marketing ploy to retail one of the first step-counting devices marketed in Japan. Yamasa Tokei Keiki Co., Ltd was founded in 1942 and produced Japan's first commercial pedometer in 1965 (YAMAX, n. d.). The trademark is 'Manpo-kei', a well-known worldwide term for pedometers (Manpo-kei means '10,000 steps' in Japanese). Regarding the popularity of self-tracking, trackers respond to a need to structure and control their health, the appeal of the degree of preciseness with which health data can be monitored, and the diagnosis of future illnesses prevented or helped. To put this simply, trackers feel reassured by their health data because this represents opportunities for interaction, interpretation and reflection on daily and personal fitness levels. For example, Lupton has observed how self-tracking allows people to pay attention 'to the details of their bodily functions and sensations, their diet, body weight, drug use and exercise habits' (2017b, p. 1). Lomborg and Frandsen (2016) observe the playful and communicative aspects of tracking in their study of self-trackers. The emotional dimensions in how trackers feel reassured and motivated to review their biometrics are highlighted in Kristensen and Ruckenstein's (2018) research.

The marketing message conveyed to users is that by adopting tracking technology, people will be able to achieve healthier lifestyles (Couture, 2021) and help prevent overburdening health services in the lives of older adults (McMahon et al., 2016; Seifert, Schlomann, Rietz, & Schelling, 2017).

When the state of one's health is recorded on an app, there is a blurring of boundaries between the quantified space of the body and one's immaterial sense of health, such as sleep patterns and mental well-being linked to feelings of fatigue, physical pain and impact of stress on the body. The consumers of self-tracking technologies can be seen as pioneers or trendsetters due to their ability to invest in new methods of monitoring their health (Hardey, 2019). Self-tracking differs from traditional sources of health advice and professional interventions in this regard. Indeed, the rhetoric surrounding similar unconventional health practices has been associated with a more natural and romanticised past, necessitating a critique and distance from the unnatural present, particularly the use and role of technology. The commodification of self-tracking reveals different motivations, where there may be some reluctance to trust information obtained outside of formal health institutions. From this perspective, the health and lifestyle choices made are seen as an extension of commodity groupings involving symbolic codes of behaviour, engagement and activities. To understand people's engagement with self-tracking, it is thus crucial to be aware of symbolic meanings embedded in tracking practices and by extension the commodification of such technologies. Tracking rewards, for example, offer intrinsic value for trackers at the level of competition with other users, and as part of direct financial reward programmes through third-party providers (Henkel, Heck, & Göretz, 2018; Hardey, 2019).

A recent Pew Internet study carried out in 2019 reported that one in five US adults regularly wear a smartwatch or wearable fitness trackers (Vogels, 2020). Since the onset of the pandemic, it has been reported that consumers are more willing to share health data Bernstein (2021). The popularity of these technologies indicates a high level of interest in personalised health data and various levels of investment in health knowledge and promotion. What once were unconventional health practices (enacted without health professionals) have become mundane and ordinary for the trackers who use such technologies daily. In the last three years, the number of connected wearable devices has more than doubled, rising from 325 million in 2016 to 722 million in 2019. By 2022, the number of devices is expected to exceed one billion (Vailshery, 2021). Traditional health interventions based on expert health knowledge are increasingly at odds with continuous access to personal health data provided by tracking technologies. As a result, tracking is frequently viewed as a further exploration of non-traditional health practices that lack a cohesive professional foundation and role in state policy. Recent commentators have noted that tracking is well-suited to neoliberal politics, in which 'subjects self-define in terms of their status for the external quantified gaze', as Moore and Robinson observed in their study of employee self-monitoring in