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Self-monitoring for health: questions for an emerging field.

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Abstract

This paper aims to contribute to critical studies of self-monitoring by drawing together existing scholarship, emerging predominantly in digital sociology and media and communication studies journals, with scholarship from Science and Technology Studies (STS) and Sociology of Health and Illness (SHI) on other health technologies used away from the clinic. We take stock of existing work and suggest potential avenues for further exploration. We start by offering a critical summary of scholarship on self-monitoring, arguing that an important theme has concerned the meaning and value of data. An initial focus on media and commercial discourses, providing political economy and Foucauldian analyses, has been complemented and complicated by emerging ethnographic work, particularly on the Quantified Self movement, which suggest plural understandings and valuations of self-monitoring data, and limits to data flows. A key contribution of our argument is that there may be more to self-monitoring than data and data flows. We suggest that a technology-in-practice perspective might help to explore the diversity of monitoring practices, bringing into relief issues that are already central in SHI and STS. We draw on evidence from comparison cases of other health technologies used in domestic spaces (telecare and pharmaceuticals) to highlight three conceptual areas that have resonance for self-monitoring: (i) non-use, resistance and unexpected uses of technologies, (ii) the distributed work of self-monitoring within existing care infrastructures, and (iii) the emotional meaning of self-monitoring. We end with a series of questions that we propose could help orientate and further enrich future scholarship into self-monitoring.

Keywords: self-tracking; infrastructure of care; technology-in-practice; quantified self; participatory medicine

Introduction

This paper poses questions about self-monitoring using technologies acquired independently of formal health services, and marketed with the promise of improving health, broadly understood. There has been both an explosion in markets for and scholarly interest in digital and wearable monitoring¹ technologies such as Fitbit, and smartphone apps logging different aspects of one's bodily existence. Alongside and to some extent prefiguring this, there has been a growth in consumer markets in what might be thought of as more clinically orientated self-monitoring devices. We have in mind here consumer

¹ Scholars tend to use the terms 'self-tracking' and 'self-monitoring' interchangeably. When discussing other scholars' work, we adopt their preferred term.

devices such as weighing scales and blood pressure monitors which have moved from the clinic into the home over the course of the twentieth century (Bivins and Marland, 2016). To this we would add a range of other devices such as oximeters and glucometers which can be bought with relative ease online and in pharmacies. Many of these may be characterised as stand-alone rather than networked devices. Discourses surrounding the breadth of self-monitoring technologies propose quite complex sets of practices in order to achieve health gains. They promise that such technologies will uncover otherwise hidden aspects of our biological lives, creating measurements of physical state and performance that may alter lay and professional knowledge, reassure or alert the user, and motivate further action such as changes to diet or physical activity.

Self-monitoring is attracting increasing scholarly interest and represents a burgeoning field of empirical study. Work to date has largely focused on networked forms of self-monitoring, has often been published within digital sociology and media or communication studies outlets, and initially tended towards analysis of discourses found in media, policy and marketing materials. More recent work has provided ethnographies of tracking—initially of particular communities such as the Quantified Self (QS) movement (Nafus and Sherman, 2014), and latterly looking beyond these communities (e.g., Didžiokaitė et al., 2017). Within the last 18 months, a number of empirical collections have been published (Nafus, 2016a; Selke, 2016; Ajana, 2017; Lupton, 2017a). Several authors offer very useful work in drawing this scholarship together into critical research agendas, with a specific focus on digital devices and the digital data they produce (Neff and Nafus, 2016; Rich and Miah, 2017; Lupton, 2017a). Our aim in this paper is to contribute to critical studies of self-monitoring by drawing together this work, with insights from sociology of health and illness (SHI) and science and technology studies (STS).

In the paper we first provide a critical account of some of the diverse literature on self-monitoring, taking stock of key empirical contributions and arguments. We characterise these discussions as focussed on the meanings and value of data, as well as having an empirical focus on networked devices and monitoring. A key argument of our paper is that there may be more to monitoring than data and data flows, and we highlight what we think are some important additional avenues for exploration. We do this by making links to critical

scholarship in others fields, which we think provide useful concepts for further thinking about self-monitoring. As we have noted, consumer self-monitoring devices might be situated both within the wider context of consumer health and wellness markets and clinically initiated self-monitoring.

We draw on studies from STS and SHI concerning technologies with varying degrees of closeness to the formal health services (telecare, and prescription and over-the-counter pharmaceuticals) that are widely used in private and domestic settings, although sometimes provided by health or care services, and relate these to emerging examples in self-monitoring. These comparison cases help further to develop questions for the study of self-monitoring in practice.

Research on telecare provides insights into the use of monitoring technologies away from the clinic, although in cases where formal health or social care services provide the technologies and guide their use. Prescription medicines exemplify a technology accessed via the clinic but used elsewhere, though with less professional oversight. However, over-the-counter medicines are squarely consumer health technologies, acquired and used at consumers' volition.

We highlight three key conceptual areas from these literatures (i) non-use, resistance and unexpected uses of technologies, (ii) the distributed work of self-monitoring and (iii) the emotional meaning of self-monitoring. We use these as a way of organising our analysis of the emerging ethnographic literature on self-monitoring. We conclude by posing a series of questions based on this analysis which we propose could help orientate future scholarship into self-monitoring. Transposing conceptual work from STS and SHI onto self-monitoring helps to open up and develop the critical agendas being posed by others.

Characterising emerging self-monitoring technologies

Consumer devices associated with self-monitoring are seen as a growth area, with uptake of digital and networked technologies predicted to increase (Neff and Nafus, 2016). In this context, policy-makers cite self-monitoring as a future fix for the high costs of formal health care (e.g., Ruckenstein, 2014) whilst technologists describe the disruptive capacities of these

technologies to 'upend the status quo of power within established industries and social institutions' (Fiore-Gartland and Neff, 2016: 101). These discourses imply major shifts in who creates and controls medical knowledge and who is seen as responsible for maintaining and managing health.

Such discourses have provided a focus for critical scholarship on self-monitoring outside the clinic. Here, we focus on some of this research to frame key issues which have come to shape a sociological conversation on self-monitoring. The selection of literature we consider is not intended to be exhaustive but to reflect key themes that we suggest have been prominent in discussions to date. Scholarship drawing on Foucauldian and political economy traditions have argued that self-monitoring data are increasingly exploited by those seeking to govern or profit from contemporary workers or citizens. Other accounts, drawing on bioethics and studies of innovation, have proposed that self-monitoring data may be pooled more idealistically as part of communal efforts to generate new forms of patient-centred knowledge. In the following sections we consider the arguments of this scholarship about the meaning and authority of data and the ways such data acquire value. We also attend to scholarly contributions that have complicated this binary paradigm in which users of self-monitoring devices are either exploited or empowered.

The value of data for those who self-monitor

Deborah Lupton (2016) provides a broad critique of self-monitoring from a Foucauldian perspective, describing monitoring as a form of surveillance that creates moral obligations that may be internalised, engendering new forms of self-knowledge, reflexive data practices and action on the self. Here, web 2.0 technologies and mobile devices allow a more detailed, intense promotion of healthism and the discourses surrounding these technologies configure certain types of neoliberal, self-regulating subjects even in the absence of particular medical conditions. Where commercial and policy discussions suggest emerging monitoring technologies will allow people greater control over their lives, Foucauldian analyses like Lupton's counter that they create new obligations.

In suggesting how this works, Lupton (2015) argues that these technologies encourage people to understand their physical bodies through numbers, rather than embodied

sensation. It is posited that numeric data or its materialisation into visual representation will likely be privileged as more objective than signs of real bodies or patients' accounts, a point Kenner draws out in her analysis of asthma apps which stand to 'strip disease...of biographical, ecological and affective detail' (Kenner, 2016: 511). The technologies configure an 'algorithmic' subjectivity, in which 'the body and its health states, functions and activities are portrayed and understood predominantly via quantified calculations, predictions and comparisons' (Lupton, 2015: 449).

While these analyses of policy and marketing discourses posit particular readings of self-monitoring data, QS ethnographies highlight the complex ways in which the producers of such data see meaning or value in their data. In their QS study, Nafus and Sherman argue that, despite fears that data will be consumed uncritically, most of the seasoned QS-ers 'in no way cede authority to the supposed objectivity of devices or the quantitative nature of sensor data' (2014: 1789). Rather than uncritically reflecting expert and commercial norms of health, these trackers interrogate received wisdoms and pursue idiosyncratic notions of well-being, with a focus on 'what works for me'. In this sense, Nafus and Sherman suggest that self-tracking may in fact work as an alternative data practice – a form of 'soft resistance' to algorithmic authority.

Sharon and Zandbergen (2016: 2) similarly critique what they see as a tendency to portray QS members as 'data fetishists' whose quantification practices are concerned solely with reducing 'all phenomena, no matter how complex, to numbers while displacing other forms of meaningful expression'. While acknowledging that the appeal of tracking may sometimes lie in the truth claims of data, they identify other forms of meaning making. They conclude that tracking may extend rather than displace the senses, enable resistance, and supplement rather than constrain what can be said. Thus, while the notion of algorithmic subjectivity implies trackers will be 'data fetishists' in thrall to numeric outputs, empirical work reveals a more nuanced relationship between tracking data and personal experiences or sensation.

Further evidence of the meaning of self-monitoring is provided in a study of responses to the use of heart rate monitors as part of Finnish consumer research. Ruckenstein (2014)

found that participants combined monitoring outputs with their local and contextualised knowledge of their daily routine, leading to unexpected outcomes. Everyday activities like vacuuming or reading children's bedtime stories appeared as periods of physiological recovery and became appreciated in new ways. This suggests that, while participants did take the outputs seriously, these were not understood in conventional terms. Participants drew on tracking data not as 'data fetishists', but borrowed their authority to give new value to underappreciated aspects of daily living.

Such contingent meanings of tracking data for users, which may not be understood in ways anticipated by device manufacturers or sponsors of self-monitoring, suggest that people might not simply cede authority to the numbers produced through self-monitoring, and the expert knowledge systems that underpin these – a plural and 'ambiguous valuation' process is at work in the QS movement (Barta and Neff, 2015: 529). While some critical scholarship worried that self-monitoring data was likely to override broader understandings of bodily functions, ethnographies suggest data are likely to be interpreted in the context of everyday understandings and subjective experiences. We note that these observations resonate with established work in SHI and STS, which have long traditions of contrasting biomedical codified knowledge with more embodied or situated lay knowledge, and understanding the way people move between these (e.g., Henwood et al., 2011). This highlights a major theme of our paper - that prior work in SHI and STS might help to foreshadow conceptually interesting aspects of self-monitoring. So far we have considered the meaning and authority of monitoring data for individuals producing it. In the following section we turn to discussions of the value of this data for others, including commercial or statutory actors.

The value of data for others

Emerging communities around self-monitoring have attracted scholarly attention beyond QS. Prainsack (2014) discusses the notion of 'participatory medicine' in relation to genomics, arguing that new forms of self-monitoring permit the explicit contribution of patients to medical innovation. She also points to observations about online initiatives like *PatientsLikeMe* that encourages people to share their own data and observations for example about symptoms, or drug responses relating to particular conditions. Through her analysis, she claims that the division between knowledge producers and recipients in the

area of health is no longer tenable; individuals may seek knowledge for self-management, but also to contribute as part of a community defined through a disease or risk status. Participatory medicine appears as an alignment of these disruptive and more conservative practices linked to commercially sponsored innovation. This complicates any simple distinction between 'good' communal knowledge production and 'bad' commercial exploitation. However, Prainsack acknowledges not everyone will join in this kind of activity, and in this sense, like studies of QS, these arguments remain somewhat limited to small and specific groups.

Lupton (2016) has more recently considered the collective aspects of tracking, drawing attention to the risk that data will be exploited. She argues that increasingly self-tracking may be initiated by others and should be understood as 'pushed' (e.g., by health professionals) or 'imposed' (e.g., by employers) on the individual. She also highlights the commercial uses of such data for market research, or by employers. Even developers of initiatives such as *PatientsLikeMe*, ostensibly participatory platforms, stand to derive value from on-selling users' information (Lucas, 2015). In starting to consider the ways in which self-tracking data from numerous sources become part of 'big data', Lupton (2016) raises important sociological questions about the forms of exploitation that may emerge as governments and corporations gain access. She thus draws attention to cases where commercial goals may be less well-aligned with those of the individuals providing the data, and where these data are not given up voluntarily. Here self-trackers appear to give up valuable data that may be used against them under the guise of personal health and empowerment. Yet there is still relatively little empirical work identifying the specific forms of reuse implied by this analysis (Lupton, 2017a).

Research to date has brought into question the exploitability of the data imagined in such accounts. Ethnographic studies of QS, for example, confound accounts of straightforward exploitation. Sharon and Zandbergen (2016), for instance, are keen to highlight that the political economic accounts of Big Data focus on its 'darker sides', at the cost of considering the valuation processes of the individuals who generate data. They are critical of accounts of self-trackers that assume they are either unaware or unconcerned by these darker, exploitative or normalising sides of tracking, which they counter through their finding of

resistance. Barta and Neff (2015: 529) echo this, highlighting how both commercial and community interests are negotiated within the QS arena, wherein the variegated practices and concerns of the QS community allow an alignment 'with commercial purposes at times and to the individual control and autonomy over data at others'. These interventions demonstrate the heterogeneity and conditionality of data value in this context.

We find much of value in these diverse critiques of self-monitoring technologies and the emerging social relations through which they come into being. They have done useful work in highlighting the disciplining/exploitative and collectivising/democratising potential of digital self-monitoring as well as the complexity of self-monitoring on the ground. Taking stock of the analytical and empirical focus of this work, we have suggested that (1) a strong focus of critical scholarship on self-monitoring to date has been on the value of self-monitoring data, and (2) this has largely been informed by analyses of marketing and professional discourses and ethnographies of QS, although there is emerging work on everyday forms of digital or networked monitoring. We argue that in order to understand the pertinence and value of data for those who self-monitor, and the moves by which data may be 'exploited', there needs to be much clearer understanding of why and how self-monitoring begins and proceeds, the types of data produced and the ways this does or does not travel away from the producer. To this end, we agree with Lupton (2017a: 3) there is scope to broaden the empirical focus of ethnographic work beyond 'members of privileged social groups'. We add that we think there would also be value in widening the forms of monitoring to be researched beyond the digital, to include the unnetworked and mundane forms of self-monitoring. As these are the forms of self-monitoring that predominate (Fox and Duggan, 2013) we think this is reason enough for them to be of interest. Further, however, attention to these currently more everyday forms of self-monitoring has the potential to offer conceptually useful insights for and points of contrast with networked forms of monitoring.

Some directions for further studies of self-monitoring

So far we have argued that the analytic focus of much scholarship on self-monitoring has been on the meaning and value of data. We would like to promote the idea that self-monitoring may not all be about data and we suggest that a 'technology-in-practice'

perspective (Timmermans and Berg, 2003) provides a useful basis for exploring what else might be going on. This recognises that devices are not simply programmes for action, but may be used in unexpected ways. It identifies the gaps between ‘the scripts’ embedded in and accompanying technologies, and the uses of these technologies after processes of domestication and adaptation (Oudshoorn and Pinch, 2003). Following this tradition, Pols (2012) suggests this requires analysts to start from an open perspective on the various possible effects of a new technology and explore contingency, negotiation, resistance and domestication as technologies become incorporated and meaningful in everyday practices. This kind of approach is endorsed in recent work on self-monitoring which seeks to explore the diversity of monitoring practices and preserve openness about the effects of increased monitoring (Nafus, 2016a). It is also found in ethnographies in which QS trackers are reframed not as passive consumers, but as active users of devices (Sharon, 2016), and touched on in recent research agendas (Lupton, 2017a). We suggest that STS and SHI offer underexploited intellectual foundations and conceptual vocabularies for pursuing research in this area.

In the rest of this paper we move from a primary focus on data and its value to propose some further directions for the study of self-monitoring. Here, we consider studies of other health technologies used away from the clinic which we think help to foreshadow potentially interesting aspects of monitoring practices. The technologies we consider are: ‘telecare’ – a form of clinical or social care practice that involves the clinic or other organisations giving patients monitoring devices to use in the home; and medicines, which include both clinical and consumer products used largely at the volition of the patients/consumers who acquire them. Though not an exhaustive list, these studies highlight three key conceptual areas which we relate to the emerging empirical studies of everyday self-monitoring: (1) the possibility for non-use and resistance to technologies (2) the work required to insert technologies into domestic spaces and routines, and (3) the emotional meanings of these technologies and practices. In each section, we tie in the small but growing body of research on everyday self-monitoring to illustrate the valuable resonances between these fields of study.

Non-use, resistance and unexpected uses of technologies

The non-use and unexpected use of technologies has been an enduring theme in different ways across SHI and STS, described through concepts including resistance (Wyatt, 2003; Pound et al., 2005), anti-programmes (Akrich and Latour, 1992) and domestication (Silverstone and Hirsch, 1992). These are set against the 'scripts' of technology promoters, including manufacturers, marketing, policy makers, health professionals, and embedded in the technologies themselves through design. Such work underscores the relative agency of users (lay people, patients or consumers) once technologies have left the factory, shop, pharmacy or hospital.

Given industry data on high rates of attrition in self-monitoring device use (Neff and Nafus, 2016), this concern seems highly pertinent in the context of self-monitoring. The importance of this theme is clear in studies of telecare, which have often included home-based monitoring of people's activities or health status, initiated by and in collaboration with health or social care agencies (pushed or imposed tracking in Lupton's terms (2016)). Non-use has been discussed, where technologies are rejected, ignored or forgotten (Milligan et al., 2011). Attention has also been drawn to examples of 'misuse' or subversion, such as setting off personal alarms to get social contact without a professionally approved reason (Milligan et al., 2011). In Oudshoorn's (2011) study of heart failure telecare, 'resistance' comes from health professionals who dislike that their work is partially delegated to telecentre workers. It also comes from patients, whose 'resistance involved a protection of boundaries between the home and the clinic' (2012: 132). In these instances, devices were experienced as disruptive of daily routines and therefore constituted an 'unwelcome intruder into the home' (2012: 133). Not only did Oudshoorn find outright non-use and rejection of telecare, she also describes its 'selective use' (2008: 282). This included occasions when patients with ambulatory ECG machines did not bother their physician when they were unsure if the problem was serious, or problems occurred during the night (2008), or when they avoided using their devices in public spaces because the noises that the machines made drew attention to their heart problem (2012).

These studies of telecare, as well as studies of the uses and non-uses of medicines (Pound et al., 2005; Weiner and Will, 2016), indicate a range of responses to health technologies intended for use away from the clinic. These include declining or avoiding use, trying and

then rejecting or forgetting, and unexpected or unsanctioned uses that do not follow the script. These points are occasionally made in self-monitoring research – for example, it is noted by Copelton (2010) in her study of a healthcare initiated older people's walking group, that members did not engage with the proffered pedometers, as these and the competition they introduced were seen as antithetical to the project of socialising and having fun, which were the main values for the members. More recently, Piras and Miele (2017) worked on the qualitative strand of a clinical trial for a diabetes home management smartphone app. They note that some interviewees were selective in their engagement with the platform, logging their data locally in the app but refusing to upload it to the server for external scrutiny, effectively building a 'wall' between home and clinic to maintain autonomy over their disease management. Such research (see also Didžiokaitė et al., 2017) demonstrates that resistances and (mis)uses might feature more centrally in sociological explorations of self-monitoring-in-practice.

People, then, may be only temporarily or intermittently enrolled in self-monitoring and may use devices in very different ways than those anticipated by their manufacturers. A key contribution of the scholarship discussed has been attending to the distance between expectations and practice. While concerns about exploitation imply that self-monitoring will permit 'data's frictionless circulation' (Nafus, 2014: 216) between individuals and governments/corporations, these studies suggest we ought to approach this expectation with care, pointing to both non- and unexpected uses. Looking out for these possibilities is a corrective to assumptions that self-monitoring will be effective in producing 'data' that will be transformed, relatively unproblematically, into valuable information for researchers, companies and governments. In the following section, we continue this theme of complicating self-monitoring by considering the range of people and things that may be involved in monitoring in practice.

The distributed work of self-monitoring

One of the major insights from STS scholarship on telecare concerns the distributed character of telecare work and the wide range of actors involved including doctors, nurses, telecare workers, patients and their families, as well as technologies themselves. This has been captured in various concepts including the 'socio-technical network of care'

(Oudshoorn, 2011; 2008) and 'care infrastructure' (Langstrup, 2013). In the context of heart failure, Oudshoorn (2012: 131) articulates the active role of partners in self-monitoring, who were 'turned into co-inspectors of bodies'. Oudshoorn discusses the gendered nature of partners' involvement: where male partners helped their wives with the technical aspects of interacting with devices, female partners supported their husbands in dealing with the emotional aspects of monitoring and adhering to dietary instructions. These different activities exemplify the 'articulation work' and 'affective work' required to insert telecare technologies into the spaces and practices of care (Oudshoorn, 2008).

Langstrup (2013) builds on these ideas in the context of the home management of haemophilia and asthma medication, to introduce the notion of the *chronic care infrastructure*. This comprises the 'socio-material arrangements' (of people, spaces and mundane objects) that allow the distribution of chronic illness management. As with telecare, she finds that the work of medication at home is gendered, as mothers and mainly female spouses help to make sure treatment is implemented. She also reminds us that home is a shared material and emotional space and observes that turning this into a chronic care space requires negotiation. This infrastructure perspective offers a useful corrective to studies of self-monitoring as an individual practice (c.f., Fox, 2015).

SHI scholars have also been interested in the distributions of 'Illness work across networks. Cheraghi-Sohi et al. (2015) apply this approach to explore how people with multiple long-term conditions manage their complex medication regimens drawing on four forms of work by patients, friends, family members or health care professionals: *medication-articulation* work, (e.g., ordering, collecting, or emplacement of medicines); *surveillance* work, for example keeping track of progress across the day; *emotional* work, supporting reasons for taking medicines (seen by study participants as expressions of care); and *informational* work, for example around new medicines or dose changes.

Linking this to self-monitoring, Weiner and Will (2017) test out a care infrastructural lens in relation to consumer home blood pressure monitoring. They highlight the range of work (articulation, emotional and informational) that partners, family and friends sometime undertake, for example in lending, gifting or recommending monitors, encouraging

monitoring, helping with the use of equipment and monitoring together. Similarly, Verdezoto and Grönvall (2015) noted that their participants shared the task of interpreting their blood pressure readings with a spouse or other immediate family members.

Bringing this infrastructural sensitivity to self-monitoring recognises that networks may be involved in prevention or health maintenance, the potential distributions and delegations of work entailed, and the potentially gendered nature of this work. It places monitoring activities within a set of relationships understood through the lens of care (Cheraghi-Sohi et al., 2015). This offers an additional perspective on the possible relationships embedded in self-monitoring compared to Lupton's proposed modes of self-tracking (2016). There a distinction is made between 'pushed' and 'voluntary' tracking. Further, although a 'communal' mode references a shared and distributed version of tracking, its focus is on data sharing, which is imagined as happening through social media, or via QS-style meet-ups, rather than the sharing of devices and the doing of monitoring as part of everyday relational and caring practices. Acknowledging self-monitoring as a material, relational practice raises questions picked up below in our final section.

First, however, we consider a set of observations about the potential role of healthcare professionals in networks of self-monitoring. While professionals are included as part of discussions of chronic care infrastructures, critical narratives about self-monitoring are less clear about the role of clinicians in data collection. A notable exception is Ruckenstein's (2015) interviews with healthcare professionals about patient-inputted data on a food tracking app. She notes that some highlighted practical barriers to the flow of data and questions about how these newer platforms might be practically embedded in existing ICT frameworks of well-established healthcare infrastructures. Fiore-Gartland and Neff highlight how patients and clinicians might have very different expectations of what data are/can do. Clinicians may not recognise the same 'actionability' that patients do in the data they produce. They also highlight the responsibility that stands to be placed on clinicians to do things with the data their patients give them, noting that one clinician 'might accept data from patients' pedometers because walking more was not risky, but he thought blood pressure or glucose readings, which could potentially demand more clinical action, were risky data' (2015: 1479).

A further point emerges from studies of medication use concerning patients' willingness to discuss their self-treatment practices, here in the context of a pluralistic market in therapies, which includes prescription and over-the-counter medicines, complementary therapies and home remedies. Work by Stevenson et al. (2003: 515) shows that patients' willingness to discuss self-treatment with practitioners depends on whether they expect these treatments to be seen as legitimate: Patients may 'fear conflict or criticism, or may not perceive [self-treatment] to be relevant'. Thus patients mostly discuss self-treatments with clinicians only if asked directly, although not always, and may volunteer information about some treatments but not others. Thus, people tend to anticipate what might be of clinical interest, and what might cause clinical disapproval. Furthermore, clinicians are not necessarily interested in their patients' self-care regimes.

Similar themes are emerging in relation to self-monitoring. Nielsen (2015) suggests in her study on home-based monitoring for patients with pacemakers that invisible 'filtration work' takes place on the part of patients who discriminate between data they think their clinician would/would not find useful before sending information back to the clinic. Unlike some accounts that imply that data produced by self-monitoring travels unimpeded to clinicians, other actors and organisations, studies we discuss here suggest patients may not, or may only selectively, communicate self-monitoring data, with varying degrees of receptiveness.

Our discussion of the work and networks of care in relation to telecare, medicines and self-monitoring suggests a need to focus increased attention on the distribution of different forms of work and to the people, things and spaces involved in self-monitoring at a local level as well as the wider networks required for exploitation. It provides an understanding of individuals as still embedded in small, personal and often local communities as well as distributed networked ones. We also suggest a need to consider when and in what ways the clinic and the home may be connected.

The emotional meanings of self-monitoring

In our discussions above, we have hinted at the emotional meanings of self-monitoring, through highlighting the relational aspects of undertaking self-monitoring and considering the ways this might be part of the negotiation of care. In this final section, we wish to draw together questions about the emotional meanings attached to monitoring, with a particular emphasis on its expressive value for users.

In her recent article on ‘affective atmospheres’ of digital health, Lupton argues for the necessity of research that focuses on how digital health ‘feels’; how does it feel to use a health app, or “to be an elderly person or person with a chronic illness monitored by a range of smart objects at home” (2017b: 8)? Conceptual foundations for the answers to both these questions, we would suggest, may be found in existing studies of telecare, where several authors draw attention to the different ‘affective’ or emotional responses to new health technologies.

For example, Pols and Moser (2009: 173) illustrate how telecare can provide individuals with a sense of safety, as well as reassurance for families. It may also be enrolled in more playful interactions. So, when an educational programme, provided as part of a telecare package, asked multiple-choice questions about the facts of the patients’ disease, symptoms or healthy living, they report:

‘patients like these questions and often turn the answering ... into a quiz or competition with other members of the household. In this way they answer questions together, and turn the event into something else than a one-way questionnaire. So even if questions and answers are structured and structuring, affective communication may take place by changing their meaning and by drawing in other conversation partners.’

Pols and Moser (2009: 176, original emphasis) argue that research should ask ‘...*what kind of affective and social relations are enabled by medical technologies. What values may the interaction with particular users bring, and what kind of affective temperature do they stage? What social relations are built with or through it, and to whom might these be of value?*’. In arguing this, they clearly link affect with infrastructures of care.

These questions are only starting to be addressed in empirically informed self-monitoring scholarship. A notable example is provided by Pantzar and Ruckenstein (2014: 106) in their research on heart rate monitoring, mentioned above, who argue that while the technology was initially conceived of as a health device, it will need to promote emotional engagement to be attractive to customers: 'The playfulness and creativity of people interacting with measuring devices and the resulting data suggest that new practices might be only indirectly related to health and well-being'. Here we see the potential for affect to co-exist with or take priority over knowledge-seeking.

Playful use has been a theme in discussions of fitness devices, where fitness monitoring can be a source of joy for the tracker, whilst being a 'social and cultural practice that is fundamentally communicative' (Lomborg and Frandsen, 2015: 1016). For example Whitson's (2013: 171) discussion of her own use of a running app describes enjoyment of tracking which is derived both from achieving individual goals and participating in a tracking community: 'My pleasure is not only rooted in my individual successes, but rooted in my shared identity as a healthy subject, part of a community that embraces similar values.' As well as fun, these apps can bring people together around competition and goal-seeking that becomes part of helping to establish and maintain an athletic self-identity (Depper and Howe, 2017). There is much more to think about in relation to the identity work that may be pursued through self-monitoring, an activity embedded in wider relational networks.

While these examples suggest fun and identity development may be found in the collective aspects of monitoring, other examples imply less positive emotional effects. In the case of telecare, considerable ambivalence is reported around the intrusion of clinical concerns into domestic life (Oudshoorn, 2012), and taking medicine is often seen as making illness more present and damaging people's sense of themselves. Thus, the storing of medication equates with 'keeping disease in the home' and may act as an 'annoying' reminder of a person's chronic disease status (Langstrup, 2013: 1015). As Langstrup (2013: 1016) describes for one of her participants, home medication provided an 'unwelcome 'elsewhere' experience at home – an obstacle to his sense of dwelling and being healthy. Treatment – and thus the disease – was something that belonged in the clinic, not to his identity and especially not to his home'. This resonates with earlier work that highlighted the symbolic

role of medicines in making illness tangible and closely linked to an illness identity (Pound et al., 2005).

It is possible that monitoring devices might also engender less positive sentiments in their users in some circumstances and evidence is beginning to emerge on this. Weiner and Will (2017) report that, like other technologies, the physical presence and visibility of a blood pressure monitor at home may occasionally be disruptive to a person's self-identity. Further while Pols and Moser (2009) describe their participants enjoying showing off devices to visitors, the visibility of monitors (Weiner and Will, 2017) or apps (Dennison et al., 2013) to others may sometimes be experienced as embarrassing or unwelcome for revealing potentially discrediting aspects of self. Thus the display value of self-monitoring artefacts appears to be quite variable. In light of all the work discussed in this section, we suggest a clearer orientation within self-monitoring research towards the symbolic roles of self-monitoring in how users conceive of and express themselves. People may derive fun from their interactions with monitoring, develop a sense of community or shared identity through online interaction, and may cultivate or protect their self-identity through the visibility or invisibility of the accoutrements of monitoring, including data, devices and software.

Looking back and looking forwards - some questions for empirical studies of self-monitoring

In this paper we have offered an account of emerging theoretical and empirical work on self-monitoring. We have suggested that initial critical social scholarship concentrated on analysis of commercial and policy discourse, but there is now a growing focus on ethnographies of self-monitoring in practice. To date, the conceptual focus has largely been on the value of data for self and for others, with an empirical focus on digital or networked forms of monitoring. Like others (Lupton, 2017a), we would welcome the continued widening of empirical focus on self-monitoring, which would mean moving beyond relatively informed and privileged patients or techy trackers to consider diverse experiences and effects of self-monitoring on the ground. We agree there is still much more to do concerning the production, circulation and value of data. To these arguments, we have added that we think studies of more mundane and unnetworked monitoring would be useful, and would have potential to shed new light on these discussions about data and its value.

We then set out to consider what insights distinctive STS and SHI sensibilities might bring to the field of self-monitoring in relation to health, drawing on studies in neighbouring fields and relating these to emerging more ethnographically informed research on self-monitoring. We highlight some key themes that we suggest could be made more central in sociological explorations of self-monitoring practices. These, we argue, would both enrich and extend current questions and theoretical perspectives. Our focus is on the temporal, material, relational and affective aspects of self-monitoring. Attention to these aspects, while not starting from a focus on data, still has important implications for its production and flow. We end now by summarising a set of questions that we think might contribute to informing future work in this field:

Non-use, resistance and unexpected uses

Like other domestic devices, self-monitoring technologies may be rejected or abandoned, used intermittently, or in ways very different from those imagined or sanctioned by manufacturers or promoters. There is scope in future studies to explore trajectories of use and non-use, as well as the specific uses made of the technologies. We can ask:

- Who is drawn into monitoring their health outside the clinic, and who is excluded or resists?
- Beyond knowledge production, what alternative uses and meanings are found for self-monitoring devices and data?
- What are the long-term dynamics of self-monitoring, and the trajectories of (non-)use of technologies over time?

Making technologies work

We suggest that health-related practice undertaken in domestic spaces tend to draw on a range of people and things. Our analysis has emphasised the work (distributed through a socio-technical network or an infrastructure of care) involved in inserting new health technologies into the home. We have highlighted the potentially complex role of local clinicians in this network, as 'patients' look to them for advice whilst gauging whether their attempts at self-monitoring will be viewed as legitimate. This casts doubt on the smooth flow of self-monitoring data to other institutions. The following questions arise:

- How are networks of people and things involved in the practices of self-monitoring?
- What new negotiations of work and care follow within and outside different households?
- How might data flows be impeded or conducted?

The emotional meaning of self-monitoring

Finally, we suggest that if one moves beyond considering self-monitoring as an individual data practice, being attentive to both unexpected uses and infrastructures, this opens up the space to consider the possible emotional or expressive engagements involved, including having fun, expressing care and demonstrating a commitment to health. Alternatively, technologies may be rejected or resisted because they demand an unwanted illness identity or reveal a discrediting aspect of self. Relating this to self-monitoring suggests the following question:

- What are the emotional and expressive effects and consequences of self-monitoring?

Conclusion

In this paper, we have argued that social studies of self-monitoring would benefit from the articulation of a set of questions informed by empirical research into other domesticated health technologies. Drawing on the traditions of STS and SHI, we hope to animate further empirical work, with a stronger focus on everyday practices of self-monitoring including both networked and unnetworked forms. We suggest this would help to illuminate how a range of actors and things may be entangled with the work of self-monitoring, and give space for unanticipated and contingent effects. By drawing attention to opportunities for resistance, alternative understandings and everyday practices, this might allow us to counter some of the expectations embedded in both commercial and policy discourse and in sociological commentary, and contribute to understanding the effects and importance of the contemporary expansion of markets promising 'health' and 'wellbeing'.

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