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Digital Consumer Health: Negotiating Multiple Voices in the Clinical Consultation

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Abstract

In this paper, we explore what may happen when people who are ostensibly "well" bring data from digital self-tracking technologies to medical consultations. On the basis of a fictional case narrative, we explore how multiple "voices", in a Bakhtinian sense of the term, inscribed in the self-tracking devices are activated, negotiated, evaluated and re-imagined in the context of care. The digital metrics "speak" precision, objectivity and urgency in ways that challenge conventional, normative understandings of doctors' professional role and the patient-doctor relationship.

Our theorizing is firmly grounded in our professional experience and informed by recent research on self-tracking, Mol's research on the ways in which technology has become integral to medical care, Bakhtinian theory and medical professionalism, and it contributes to current professional debates regarding medical overuse and its potential to harm patients. Further research is needed to illuminate the consequences of digital self-tracking technologies for patient-professional consultations in practice.

Keywords

Medical professionalism, professional responsibility, health technologies, digital consumer health, Bakhtin

Case story part I: Thomas makes an appointment with his doctor

Thomas is a petroleum engineer, employed by an oil company. When not at work, he spends a lot of time engaged in physical training, especially running. It is important to Thomas to be in good shape. He keeps an ambitious, scrupulously planned exercise programme, and runs 10 km five times a week. He takes part in a couple of marathons every year and is now training for a triathlon.

Although Thomas is very fit, he has become worried about his health. His motivation in preparing for the triathlon has dwindled, and in the evenings when he examines his pulse graph on his laptop, he can see he is not progressing optimally. His anaerobic-threshold sessions have improved since summer, but not in line with his training plan. Thomas decides to visit his general practitioner (GP) for a check-up.

When Thomas attends his appointment, he brings a colour printout of his in- and post-training pulse recordings. Amber readings indicate sessions that are sub-optimal; there are several amber sessions. Thomas explains his concerns to his GP.

Scope, methodology and theoretical perspective

The medical encounter is traditionally conceptualised as a communication dyad between clinician and patient. The presence of technologies in medical consultations challenges the patient-clinician dyad, with human and non-human agents jostling for attention in an increasingly crowded "health market" (cf. e.g. Statista, 2021). In this paper, we explore how digital consumer technologies for self-monitoring or self-tracking such as those used by Thomas in the case story above may affect the professional-patient relationship in medicine. We investigate how these technologies may challenge general practitioners' ability to act in their professional capacity. Specifically, we consider the ethical commitment to help patients with their health concerns whilst at the same time protecting them from harm from over-investigation and overtreatment. The case narrative is an exemplar derived from our collective professional experience. SH and DS are academic general practitioners with 20-and 27-years clinical experience, respectively. KL is an educator with professionalism as a field of expertise.

The narrative we present at the centre of our critical analytic thinking is not based on one particular clinical case, nor is it empirical data arising directly from a research project. To this end the case is fictional. However, it is inspired by and grounded in our professional

experience, gained individually and as members of a professional community, and informed by our shared ethical concerns and interest in philosophical medical anthropology.

We constructed the exemplary narrative iteratively; it has developed in tandem with our conversations, critical reflections and reading of relevant commercial and academic literatures. For example, as clinicians, we (SH, DS) encounter parents who bring Excel printouts of their children's temperature recordings, patients who refer to nocturnal recordings from their Fitbit as they request sleeping pills, and people like Thomas, concerned about their heart health, fitness and performance. As academics we are curious about how technologies shape social practices; a question that may profitably be explored from an ethnographic perspective (Greenhalgh & Swinglehurst, 2011; Swinglehurst, Greenhalgh, Myall, & Russel, 2010), and we share a concern for the pitfalls of medical overuse.

Our approach is similar to the common design practice of "evoking ideas for possible futures" (Dindler & Iversen, 2007) and the construing of case narratives to speculate on the potential benefits of technologies in-the-making, the "sociotechnical imaginaries" that are the subject of the sociology of expectations (Hedgecoe & Martin, 2003; Jasanoff & Kim, 2015). We are also inspired by Prainsack, who uses case narratives of two students (one authentic, and one a fictional composite of real stories) in her persuasive investigation of whether and how consumers and patients are empowered by digital technologies and other forms of commercial surveillance (Prainsack, 2017). We combine this narrative construction with critical thinking about the challenges and unintended consequences of digital self-tracking technologies for patients, general practitioners, and the relationship between them. All three authors have made use of and developed this methodology in their previous work (Hjörleifsson & Lea 2017; 2018; Swinglehurst & Hjörleifsson, 2018).

Inspired by Bakhtin's theory of dialogicity and polyphony, we employ our fictional case narrative to theoretically explore the idea of self-tracking technologies delivering a novel "voice", or a plurality of voices into the clinician-patient encounter, extending previous work that conceptualised the electronic patient record as collection of voices (Swinglehurst, 2014). We focus on the interaction between the patient, clinician and self-tracking devices and consider the following questions:

- Whose voices are inscribed into self-tracking technologies and how do these voices affect the meaning of medical professionalism?
- How do these voices shape the relationship between patients and doctors?
- How do the parties (patient, doctor and digital self-tracking technology) share the responsibility for the patient's health, and from where does this responsibility derive?

Bakhtin's notion of the dialogic nature of communication regards spoken and written utterances as inevitably responding to and anticipating other utterances. Meaning is only possible at the point at which speaker and listener (or reader and writer) connect, cannot be reduced to either one of them, and is always embedded in a social, cultural and historical context. Utterances are characterised by polyphony, "a plurality of independent and unmerged voices" (Bakhtin, 1984b, p. 6), and are an appropriation of the voices of others, with speakers populating their utterances with their own expressive intentions. Voice, for Bakhtin, is the dialogically constituted "speaking consciousness" and he regards the ideological becoming of a human being as an ongoing process of assimilating and appropriating the words of others. Further, Bakhtin relates speakers' power to the extent that each of them can "temporarily arrest the multivocality of meaning within discourse" (Steinberg, 1998, p. 855), privileging certain meanings whilst suppressing alternatives. Our case narrative, while fictional and speculative, illustrates some ways in which—as expressed by our "voices", modulated by our academic and other surroundings—the voice of selftracking technology may arrest other meanings that previously have been privileged in doctor-patient encounters.

Our analysis is also influenced by the research of Mol (2003; 2008) on the diverse ways in which technology has become integral to medical care. Drawing on close observations of medical practices, Mol's key claim is that patient-doctor-technology relations are multiple and inherently subject to tensions and ambiguities that are particular to each setting and technology. Technology is integrated into care through iterative ongoing negotiations and adjustment by patients and professionals, rather than by following a blueprint inherent in the technology itself or by simply "implementing" it. While we share many of Mol's perspectives, our analysis focuses on self-tracking technologies in a specific context of use, by people who are ostensibly fit and well. In this case, the threat to the health of the person seeking help is far less obvious than in the case of diabetes and other chronic diseases that are the subject of medical care in Mol's studies. Our intention is to carve out what is at stake in some of the negotiations and adjustments that are necessitated as the voices of self-tracking technologies enter the consulting room along with patients whose health concerns are closely interlinked with output from these same technologies.

Also relevant to our argument is Mol's distinction between the "logics" of choice and care. Mol points out that when individual choice is celebrated as an ideal in health care, people seeking professional help are portrayed as customers or citizens. This contrasts with the collaborative and continuous attuning of knowledge and technologies to diseased bodies and complex lives—the "logic" of caring for patients. From this perspective, choosing and "consuming" technological products is different to negotiating and recursively adjusting the use of technology as part of medical care. In the logic of care, technology needs to be handled with elaborate care for the purpose of patient care. Our case narrative illustrates possible consequences for care as digital self-tracking technologies "speak" on behalf of

consumer choice in the consulting room. We will explore potential tensions between these and other voices that participate in doctor-patient conversations.

Self-tracking, health and healthcare

Self-tracking devices that measure, quantify, and record physical data such as pulse, blood pressure and movements during e.g. exercise and sleep are popular. In 2015, one in five people in the United States reported using a wearable self-tracking device (Fleming, 2015) and sales reports indicate that similar figures apply in Europe (Prainsack, 2017). No longer limited to single purpose devices, digital self-tracking has expanded through the use of apps in smartphones, using either built-in sensors or inviting the user to enter data (Lupton, 2017). Collecting, analysing and sharing activity data is integral to the design of many mobile phone apps, and extensive tracking is often enabled within mobile phones by default.

Self-tracking shares essential features with the medically sanctioned collection of physical data about patients while they are outside of healthcare institutions. Examples include the measurement of blood glucose in some patients with diabetes to enable better treatment with insulin or the diagnosis of cardiac rhythm disturbances using an ambulatory electrocardiogram. However, even for patients with overt disease, the benefit of gathering and analysing physical data over time varies and is frequently contested. Not all patients with diabetes benefit from regular blood glucose measurement; it is not recommended for patients who are not insulin dependent (NICE, 2019). Similarly, in the absence of history of cardiovascular disease only a small fraction of younger people may derive any benefit from searching for cardiac rhythm disturbances (Jortveit et al, 2020).

When it comes to digital self-tracking, i.e. measuring, quantifying and recording physical data, among people who are currently well, there is scant evidence that the data gathered can be used to improve health. Nevertheless, health benefits frequently feature in promotional materials related to digital self-tracking, e.g. "these trackers were made to help you live a healthier life" (Fitbit, 2020) and "all-day health monitoring" (Garmin, 2020), and it is likely that Thomas is familiar with such claims. Thomas's GP has a dilemma because she is working in an evidence-free zone. No research has shown whether or how data of the kind that Thomas brings to the consultation room can assist diagnosis or treatment. The GP has to deal with the worried patient who may feel that his printout warrants further medical investigations. She also must balance this alongside her orientation towards "evidence-based medicine" in a context where there is no reliable scientific evidence to help. What is she to make of the patient's pulse recordings and the amber alert that implies some of Thomas's training sessions are sub-optimal?

Self-surveillance is not new; we all do it. The little headache that I felt earlier, is it still there? Is the strain in my neck annoying me enough that I want to change my position? Am I feeling tired and unwell because I have the flu coming on, or have I just been overworking? These are familiar examples. What is new is the move towards systematic self-surveillance with

wearable and other digital technologies supporting quantification, storage, analysis, sharing and commercial use of self-surveillance data (Lupton, 2016 p. 10).

The "quantified self"-movement illustrates many of the ideas and activities associated with self-tracking. The "quantified self" is a loosely defined, internet-based social movement which embraces both the social and the digital-systematic dimension of self-tracking with discussion fora, regional meetings, and blogs supporting self-tracking and personal data sharing (Lupton, 2017a, 2017b). The movement's website declares that it "supports every person's right and ability to learn from their own data". Not only is self-improvement a central aim, but the act of collecting and quantifying self-tracking data is implicitly framed as a duty in the service of one's right to learn from it. Members upload self-tracking projects to the website, inviting comments from the wider membership of the network. Within eight years of this website's development, the social movement had grown to include 207 quantified self-groups in 37 countries, with 52,000 members (Lupton, 2017a). The term "quantified self" in addition to referring to a specific network has also become a common noun, referring to a collection of practices.

Research on self-tracking

There is growing academic interest in self-tracking practices, especially those related to well-being and health (e.g. Dijck & Poell, 2016; Ruckenstein & Schüll, 2017). This research tends to direct attention either to the structural level (e.g. how big data influences social structures and everyday life) or to the individual level (e.g. how specific self-tracking practices affect users' everyday lives). At the structural level, academics have conceptualised self-surveillance practices as a facet of neoliberalism, arguing that self-monitoring and digitalization lead to a "control society" (cf. Ruckenstein & Schüll, 2017). Studies of individual self-trackers (e.g. Sharon, 2017) suggest that self-tracking is more popular among people with relatively high income and have shown that younger people primarily use self-tracking for fitness whereas older people are more prone to incorporate self-tracking into their efforts to improve health and extend their lifespan (Eysenbach, 2001; Lupton, 2017a). A critical social science perspective that considers how digital self-tracking technologies are likely to influence professional reasoning, professional practices or the scope of clinical practice seems to be missing.

More broadly speaking, digital technologies have come to affect (Erlingsdóttir & Lindholm, 2015; Saukko, Farrimond, Evans & Qureshi, 2012) and are likely to affect (e.g. Eyal, et al., 2019) health care services, patients, and health itself in profound ways. Quantified electronic data increasingly "permeate and exert power on all manner of forms of life" (Iliadis & Russo, 2016, p. 2) in societies that are digitally networked. State and corporate institutions use digital surveillance of biological variables in multiple ways to shape and modify human behaviour (Ruckenstein & Schüll, 2017). Some scholars regard digital tracking devices as examples of "technologies of the self" (Foucault, 1988) contributing to an

increasingly digitized biopolitics (Lupton, 2016) in which individuals participate voluntarily in processes of biological self-government (Foucault, 1986) or digital self-regulation without necessarily appreciating the reach of their interventions. The Quantified Self network encourages an "intense focus on the self and the body" (Lupton 2017a, p. 35), through which participants learn to "feel" their bodies or gain insights into their selves through datagathering. Participants in this practice may challenge accepted norms and categories about health and behaviour, and they may start to redefine what is considered relevant information through their individualised data practices, often being moved to act on the information they retrieve from their apps.

In our fictional case narrative, Thomas has started to appreciate the quantified data about his pulse rate and training sessions as central to his understanding of himself, and who he is as a person. He worries about the implications of the data and assumes there is something wrong with his health. This data, and how it is presented in the app, prompts him to see his GP. Thomas's data practices and his ideas about his health have become closely entangled.

Patients such as Thomas present a concern which aligns poorly with traditional models of the role of professional and patient or their relationship with each other. Saukko argues that digital health "configures its consumers as 'co-creators' of health data and knowledge together with companies and other consumers" and "frames medical knowledge as tentative, up for revision and scepticism by expert and lay science" (Saukko et al., 2012, p. 560). This is the landscape in which Thomas and his GP navigate, and it appears both parties become frustrated along this journey.

Sensations, symptoms and culture

Medical anthropologists hold that bodily sensations are culturally shaped (Andersen, Nichter & Risør, 2017). Making sense of sensations and reacting to them is learned, and this learning takes place in a particular context. According to philosopher of medicine Canguilhem (1978), this sensemaking and the culturally mediated ability to interpret and react to physical sensations often occurs at an unconscious level and is part of life. There are parallels with Bakhtin's view of dialogue, in a verbal-physical sense as being fundamental to life:

To live means to participate in dialogue: to ask questions, to heed, to respond, to agree, and so forth. In this dialogue a person participates wholly and throughout his whole life: with his eyes, lips, hands soul, spirit, with his whole body and deeds. He invests his entire self in discourse, and the discourse enters into the dialogic fabric of human life, into the world symposium (Bakhtin, 1984a, p. 293).

Culture is the conceptual and social framework that provide people with repertoires of sensing and reacting to biological states. Such repertoires help us adjust and respond to our current condition, and they inform decisions about whether to seek professional help.

Cultural repertoires of how to interpret sensations are not static, however. Under current conditions their evolution is brought about to a significant extent through commercial products and technologies.

Thus understood, technology has become a crucial part of the socio-cultural milieu in which we interpret and respond to ourselves. Technology does not simply represent states of affairs but actively constitutes them in a recursive fashion. Data from self-tracking technologies and our seeing them with our own eyes is part of the cultural shaping of "symptoms". It may cause distress, and the gadget offers a legitimate warrant for seeking help. The technology may contribute both to the patient's concern and to the authority of the patient's story about his concern, as these are entangled. It may influence not only how people experience themselves but also how they present their bodies and their experiences to doctors, whose judgment may also be influenced by the technology.

So, this insight from cultural and medical anthropology is crucial: People's experience of themselves changes as cultural conditions change. The context in which people are embedded "shapes embodied knowledge—how people view themselves and their bodies in relation to their medical experience, including treatment options, coping strategies, and relationships with those providing medical information and care" (Sulik & Eich-Krohm 2008, p. 15-16). It follows that an encounter between a patient and his doctor in a technology-enabled society differs from a similar encounter in a pre-technology era. The difference arises not only in so far as technology becomes available to deal with a given problem, but also in a more fundamental sense because the technology has already influenced how the agents perceive themselves and what they perceive as "the problem".

We return to the case narrative.

Case story part II: The doctor, the patient and the fitness app printout

Thomas is sitting in his GP's consulting room. He has described his worries and gives the doctor the printout of his pulse recordings. The doctor looks at it. She notices it includes minute-by-minute information about training intensity based on GPS tracking from Thomas's watch."What do I know about heartrate and triathlon training schedules?" she thinks to herself. The doctor senses a dull pain in her head. She tries to figure out if the colour codes in the printout somehow reflect the ratio between Thomas's pulse and the intensity of his training. Is it really that simple or are there other parameters that also determine the overall "colour" of the training session? She notices that many of the amber sessions have been conducted during weekends or on Thursdays.

The doctor eases her chair backwards. Thomas leans over the desk and draws her attention to a separate page where he has collected comments from expert members of the digital tracking community. Thomas explains that the community is a bit like the Strava

community. The GP is familiar with Strava, as she has the Strava app on her smartphone and has been using it recently to track her own cycling tours. But in Thomas' app, members gain "expert" status according to an algorithm that considers the quantity and the quality of their training as well as their maximum results.

At the bottom of Thomas's page of expert comments are some additional comments from the artificial intelligence module in the fitness-tracking app itself. Finally, there is a legal disclaimer.

The doctor draws a deep breath. She asks Thomas about his training schedule, measures his blood pressure, and places a stethoscope on his chest. While punching the results into the computer, she considers what to say next. Based on her prior knowledge of Thomas and the information he has shared with her in this consultation, she thinks it is highly unlikely that medical intervention is advisable. But Thomas leans forward once again and points to the graphs representing the first three weeks following his summer holiday. "Here, I really ought to have been making progress. It makes no sense that I am not improving. Look! All these sessions include a period when my pulse exceeds 160. It just doesn't make sense."

Perhaps Thomas needs to take it a bit easier, the doctor thinks to herself. Or maybe his expectations need adjusting. One cannot expect endless improvement, especially if one is already as fit as Thomas! And how important are the figures from Thomas's pulse watch, anyway? She asks Thomas whether has been feeling less energetic or whether there are any other indications that something is wrong aside from the pulse readings. She realises Thomas may dislike it if she does not appear to take his printouts seriously. Thomas's frustrated response is that the unfavourable pulse readings provide ample evidence that something is wrong. He becomes impatient and gets the impression that the doctor is struggling to understand the printouts. "Let's do some blood tests", Thomas suggests "and an ECG! Or maybe you could refer me to a specialist?"

At the end of the consultation, neither party is satisfied. The doctor thinks she did not get through to Thomas, and that she was unable to offer real help. Although the data from the fitness-tracking app were indeed confusing, she doubts they indicate ill health. Thomas feels the doctor did not understand him. He considers making an appointment with a private clinic. He remains convinced the training logs and pulse recordings show something is wrong; one cannot dismiss plain numbers.

The voices in the consulting room

We have presented Thomas as a conscious and conscientious health consumerist patient. In a sense Thomas feels sure of his ground because his request is supported by app measurements. Thus understood, Thomas' technological device lends its voice to Thomas; it is *ventriloquated* (Coreen & Sandler, 2014). Empowering him in his help-seeking it becomes part of his own reasoning and constitutes a particular reality in the moment.

What Thomas may not fully consider is that the voice of his technology must originate somewhere. Human beings and their artefacts are culturally and historically embedded; they do not exist in a vacuum. Manufactured devices are imbued with knowledge, assumptions and choices. Designers of self-tracking devices must decide which metrics to focus on, how to define "normal" and how to register and represent biological parameters. A fitness app cannot be made without reference to the notion of fitness, and the definition of fitness inscribed in the application will influence where distinctions are drawn between "good" and "excellent" performance, between a "normal" and "abnormal" pulse rate. Although an inanimate object, the device cannot make measurements or represent them from a point of nowhere. There is an underpinning logic, a mode of knowing, observing and interpreting the world; the app introduces a "voice from somewhere". Ruckenstein & Schüll describe such devices as displaying a kind of agency or "liveliness when they guide and shape a 'given tracked phenomenon according to their classificatory and procedural logics' and so 'structure and shape possibilities for action'" (2017, p. 268, referring to Williamson, 2015, p. 141).

Through this lens, the "liveliness" of Thomas' self-tracking device follows a logic that speaks into the consultation and thus takes part in structuring and shaping the possibilities for action for both GP and patient, creating opportunities and constraints. The data is afforded an aura of objectivity and authority in so far as the device's meanings become privileged whilst alternatives are suppressed. A device that measures "objectively", delivered into a medical context which is increasingly governed by the imperative to act on "evidence" holds a seductive and authoritative appeal. It may thus establish its agenda and "temporarily arrest the multivocality of meaning" (Steinberg, 1998, p. 855) and suppress other interpretations of Thomas' health situation.

We do not imply that self-tracking apps speak with a single voice. The documents Thomas shows his GP are products of a complex technology developed collaboratively by many agents. The manufacturer is likely to be a large corporation comprised of different departments, each bringing their own professional lenses, meanings and interests—marketing, public relations, graphic design, business, programming, behavioural psychology and others. Its design may have been informed by an extensive programme of "user experience" involving many stakeholders.

The range of motives and goals that coalesce in the pulse-rate recording device and fitness app is hidden behind the metrics and hardly evident to Thomas or the doctor who are invited to act on the data. Thomas may find certain strands of meaning more conspicuous and appealing than others. At the same time, the device may "speak" to Thomas with a certain ambiguity that remains confusing. The app's imperative message, conveyed in amber columns that carry a cultural weight of significance, has concerned him. But although it provokes action, it falls short of making a diagnosis or prescribing what should be done in medical terms. The app also communicates further imperatives: to maximise physical

function; to engage with the self-tracking community in a novel form of social participation. This is a logic of optimisation, self-efficacy and consumption, with rather tenuous links to health and healthcare. Thomas's motivation to seek professional help emerges from a need to repair the disconnect between the report from his fitness app and his desire to take care of his health and fitness: How do these data pertain to my health? How should I act to do what is right for my body and my wellbeing? Thomas feels unable to answer such questions single-handedly. From this perspective, Thomas may be more interested in what his GP can offer in terms of interpreting the printout than we have conveyed thus far.

Self-monitoring of bodily sensations long pre-dates the arrival of digital self-tracking applications and helps people to adapt their behaviour in ways that attend to biological needs. From the perspective of a hermeneutics of health, people seek medical aid when their capacity to interpret their own biology is exceeded or they become distressed about something they perceive as health related. In this context the GP acts as "interpreter of stories", helping patients to interpret their bodies, and working with patients to identify appropriate responses (Heath, 1995; Hjörleifsson & Lea, 2018). On this account, Thomas needs his GP to listen so attentively that she recognises his distress. The GP thus need to acknowledge and respond to Thomas's concerns, and help him interpret the data in the printout.

According to Bakhtin, all utterances are polyphonic (e.g. Bakhtin, 1977; 1984a; 1986; 2003); they carry more than one meaning and stem from more than one source, or voice. When Thomas explains what he wants his doctor to investigate, there are at least two immediately audible voices in his presentation—that of the app and that of Thomas' own concern. The app, as we established earlier, is itself a collection of diverse voices, a gathering of several different strands of meaning. In addition, Thomas is at one and the same time requesting urgent action (blood tests; electrocardiogram; referral to specialist) whilst also making a query about how to interpret the data. The patient's own experiences and concerns, themselves an appropriation of many voices, are brought into the room. The doctor's input is likely shaped by a somewhat incongruent dialogue between what the medical evidence says (or fails to say) about self-tracking data, her duty to honour patient perspectives, her own lived experience of using a similar device for cycling, and her previous experience of consultations with Thomas. The doctor's voice may also carry traces of various institutional discourses, including the current workload in the surgery and the distribution of limited resources such as time, expertise and treatment options.

The frustrating conclusion of Thomas' consultation can be interpreted as a dissonance between the leading voices in the consultation room. For the GP, the voice of the self-tracking technology raised an insurmountable challenge. Thomas' appropriation of its imperative to act, its urgency and the potential severity of its message did not leave room for her professional voice. Conversely, Thomas felt that the GP exercised her professional authority to close avenues of dialogue and action that he thought would be helpful.

Digital technology, patients and doctors

Modes of communication within the doctor-patient relationship have been changing for some time (Swan, 2009). Long before the coronavirus pandemic (2020), medical online services were being promoted in many countries promising "safe health care on your phone for delicate issues", "help within minutes", and "on mobile in minutes 24/7" (see the webpages of Medicoo, Doktor.se and GP at hand respectively).1 The pandemic has prompted a massive shift towards remote consulting using videolinks, telephone and asynchronous digital messaging. At first glance, instant advice from an online doctor for a minor health issue may be convenient and appropriate, while in other situations the loss of the physical examination may prevent important medical work (Hyman, 2020). In more complex scenarios, online consultations in which patient and doctor are not even able to see each other risk squeezing out the relational and emotional work of consulting (Casey, Shaw & Swinglehurst, 2017). If such work is crucial to understanding the patient's complaint—and there is plenty of evidence to suggest it is (Stewart et al., 2013)—then if left unattended it is possible that the consultation fails both patient and doctor.

Digital technologies such as self-tracking apps may also change consultations between patients and doctors, albeit in a more insidious manner. The predominant logic underpinning the design and "liveliness" of self-tracking technologies is that of proactive health consumerism. Thomas's device foregrounds "personal responsibility, proactive and preventive-conscious behaviour, rationality, and choice" (Sulik & Eich-Krohm, 2008, p. 6). Within this logic, the reach of responsibility goes beyond that of the traditional role of a patient as a suffering person in need of medical help (Heath 1995). Writing from a Northern-American perspective, and tracing health consumerism to the 1960's and 1970's, Sulik & Eich-Krohm explain:

Individuals and lay interest groups began to challenge the authority of experts and the dominance of the medical system. As consumers, individuals who used health services would be empowered to play an active role in making informed choice about their health. The social transformation from patient to medical consumer occurred as the term 'consumer' became the label of choice within health and social services and the medical system became increasingly more complex (2008, p. 4).

Central to health consumerism is the notion of empowerment: "lifestyle technologies emphasise our ability to enhance one's physical or mental capacities, orienting individuals towards practices of monitoring, in pursuit of 'wellness" (Ruckenstein & Schüll, 2017, p. 268). This view echoes both the self-improvement ideal of the quantified self-movement and the medical consumer role. Saukko (2018) draws an outline of what may be termed a digital health technology logic that configures its users simultaneously as consumers and as "co-creators of health data and knowledge'. When people buy self-tracking devices they buy

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¹ Links in reference list.

into this ideal of empowerment and the promise of improved capacity to "choose" one's own health and wellbeing.

Ruckenstein & Schüll suggest that "in the clinical context, self-tracking can balance or adjust the power dynamics" (2017, p. 267). When fit, well people like Thomas present the output of self-tracking technologies to doctors they stretch the boundary of what is usually open for discussion in a medical consultation. They present bodily measurements about which the professional does not "know" what to do. Thus, self-tracking data may disrupt "previously defined distinctions between patient and consumer, device and data, and health care and personal wellness" (Rich & Miah, 2016, p. 86). The technology forcefully articulates the logic of consumer choice in a setting where the logic of care has usually predominated, although arguably it has at some level also prompted Thomas to "suffer" and experience a sense of disquiet with his body, for which the GP must find capacity to "care".

Doctors' professional duties are different from those of service providers such as hairdressers or travel agents, and the consequences of offering poor medical advice—or failing to follow excellent medical advice—may be complex and serious. Consumerism cannot be the paramount logic in patient-doctor relationships. Unless both patient and doctor realise this, a mismatch of purposes like that between Thomas and his GP may arise. Thomas' reasoning aligns with the medical consumer role and the self-optimizing ideals described above. At the same time, he is trying to negotiate this role with that of a patient in need of care (cf. Lupton, 1997). The empowered consumer voice jostles with the voice of the more vulnerable patient who seeks out a doctor when he felt that his capacity to take care of his own health is exceeded. Negotiations between these differing voices may be hard to bring to a conclusion that is to everyone's liking. When the GP appears to dismiss the printouts, Thomas may well feel that she dismisses his project as a self-tracker, a project which is imbued with direct and tacit claims to responsible citizenship: personal responsibility for one's health; proactive behaviour; rationality and the right to choose. To dismiss all of this is not just a matter of Thomas' printouts; it may well feel like a belittling of Thomas himself.

The professional role of doctors

Health consumerism presents a challenge to the professional role of the doctor. How a doctor handles dilemma such as those Thomas presents is not just about the care of the individual patient but about what it means to be a professional—the lived experience of professionalism. This aspect of medical consumerism and health technology needs greater scrutiny. Although several scholars have discussed the consequences for patients—including their possible empowerment (e.g. Prainsack, 2017)—we have been unable to find research that specifically addresses the consequences for doctors, their professional role, and their scope of practice.

If one listens carefully, one can always hear a number of voices in a doctor's consultation room. The policy foundations of the profession, public requirements and medical teaching instil a duty to attend to patients' concerns and requests while also adhering to biomedical evidence (Frank, Snell & Sherbino, 2015). As long as patient preferences can be reconciled with how the problem at hand looks from the perspective of medical knowledge, this is not problematic. However, as our case narrative illustrates, there are situations when patients make requests for action which medical knowledge may suggest could be harmful—or where at least there is no medical knowledge to support the actions requested. What should a doctor do to act in her patient's best interest when the patient is determined to rely on his data rather than on his doctor's advice? Is it good patient-centred practice to comply with the patient's wishes, based on the data he has collected or should a doctor's decision be based primarily on her medical knowledge and her knowledge about her patient's health and life, with the attendant risk of losing the patient's trust? How should a doctor act when the relationship between data and knowledge is unknown or unclear? Where could the different options lead, medically, legally and ethically?

If quantified biological data from self-tracking technologies that represent a state of normality in a human being are presented as pathological or used to leverage medical investigations or treatment that is unnecessary and potentially harmful—this implies that an external technology has acquired an authority that surpasses the moral principle of nonmaleficence (primum non nocere; first of all do no harm). This would challenge the professional ethic of doctors, their professional role, and patients' expectations to doctors and the health services. In our case narrative, the information that the GP gleaned from interviewing him did not suggest that Thomas' health was threatened or that he needed any medical tests. The GP knows that submitting people to unnecessary tests and investigations can bring more harm than benefit. She is also aware that the better the health of the person who undergoes testing, the more likely it is that any finding she unearths will be a false lead (i.e. false positive) and bring with it the peril of further investigations or overdiagnosis. There is ample evidence that excessive tests, diagnoses and treatments frequently harm people through adverse effects of interventions, psychosocial impacts of labelling, and disproportionate burden of treatment (May, Montori & Mair, 2009; Morgan, Dhruva, Coon, Wright & Korenstein, 2019; Welch, Schwartz & Woloshin, 2011). The GP's reluctance to accommodate Thomas' requests for an electrocardiogram, blood tests or referral to a specialist thus arises from a well-founded professional judgement that this may do more harm than good. However, she risks being accused of not taking Thomas's perspective seriously despite trying hard to ensure the patient's best interest. When patients like Thomas bring their self-tracking data to their doctor with a ready interpretation stating the presence of a health problem or a risk to the patient's future health, this can be a strong challenge to the doctor's professional role if the doctor's interpretation of the data disagrees with that of the patient's technical device. Self-tracking technologies are marketed as beneficial for the customer and may exacerbate this potential conflict. The technologies

promise to "add value to everyday life in the form of physical wellbeing" (Gilmore, 2016, p. 2525). If the doctor questions the results delivered by the device, she may appear not only to criticise the patient's self-tracking activities, but to position herself in opposition to public health messages which call on public to become responsible citizens and "health consumers".

Conclusion

Using our fictional case narrative as a point of departure for our analysis of digital self-tracking as a contemporary social phenomenon, we have identified novel voices that may come to participate in consultations between people who are ostensibly fit, and their doctors. We have indicated that these voices may argue on behalf of health consumerism, presenting extensive data as medically relevant although neither patient nor doctor have the means of interpreting this data to make sense of what importance it may hold for someone's health. There is already evidence that the professional authority of doctors to prevent wasteful and harmful over investigation and overtreatment is under threat. We argue that the persuasiveness of the technological voice is such that it may temporarily arrest or silence other voices, making it difficult for doctors to act in their professional capacity to resist unnecessary and potentially harmful investigations or treatment.

The scenario that we put forward in our fictional narrative is one that is likely to become more common as digital self-tracking gains popularity. Whether or not the data is presented to doctors within consultations, the voices of these technologies are becoming influential in contemporary culture and have consequences for how people relate to and interpret their bodies and what help they expect from health professionals. Further research is needed which adopts a sociotechnical perspective, explores the "polyphony" in the consulting room and attends to the ethics of self-tracking practices in order to support constructive interaction between patients and clinicians to promote patients' health. Clinicians and members of the public need access to a common, cultural pool of understanding that illuminates the origin of these voices and the interests that motivate them. This might shift the conversation, enabling patients and doctors to evaluate together whether, how and to what extent the messages delivered by self-tracking devices are helpful, and when it is appropriate to act on them or resist them.

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References

- Alftberg, Å., & Hansson, K. (2012). Introduction: Self-care translated into practice. *Culture unbound. Journal of Current Cultural Research*, *4*(3), 415-424. https://doi.org/10.3384/cu.2000.1525.124415
- Andersen, R.S., Nichter, M., & Risør, M.B. (2017). Introduction. Sensation, Symptoms and Healthcare Seeking. *Anthropology in Action*, *24*(1), 1-5. https://doi.org/10.3167/aia.2017.240101
- Bakhtin, M. (1977). The Problem of the Text (An Essay in Philosophical Analysis). *Soviet Studies in Literature*, 14(1), 3-33. https://doi.org/10.2753/RSL1061-197514013
- Bakhtin, M. (1981). The dialogic imagination: Four essays. Austin: University of Texas Press.
- Bakhtin, M. (1984a). Problems of Dostoevsky's poetics. Minneapolis, MN: University of Minneapolis Press.
- Bakhtin, M. (1984b). Rabelais and his World. Bloomington IN, Indiana University Press.
- Bakhtin, M. (1986). Speech genres and other late essays. Austin: University of Texas Press.
- Bakhtin, M. (2003). *Latter og dialog. Utvalgte skrifter* [Laughter and dialogue. Selected writings]. Oslo: Cappelen akademisk forlag.
- Bakhtin, M. (2010). Toward a Philosophy of the Act. Austin: University of Texas Press.
- Balint, M. (1955). The doctor, his patient, and the illness. *The Lancet*, *265*(6866), 683-688. https://doi.org/10.1016/S0140-6736(55)91061-8
- Canguilhem, G. (1978). On the normal and the pathological. Amsterdam: Springer.
- Casey, M., Shaw, S., & Swinglehurst, D. (2017). The use of virtual online consultations in general practice: A mixed methods case study. *British Journal of General Practice*, 67(664) 7,36-743. https://doi.org/10.3399/bjgp17X693137
- Coreen, F., & Sandler, S. (2014). Polyphony, ventriloquism, and constitution: In dialogue with Bakhtin. *Communication Theory* 24(3), 225-244. https://doi.org/10.1111/comt.12041
- Dijck, J.V., & Poell, T. (2016). Understanding the promises and premises of online health platforms. *Big Data & Society*, *3*(1). https://doi.org/10.1177/2053951716654173
- Dindler, C., & Iversen, O. (2007). Fictional inquiry design collaboration in shared narrative space. *International Journal of CoDesign*, *3*(4), 213-234. https://doi.org/10.1080/15710880701500187
- Doktor.se. (2020, January 21st). Doktor.se. Retrieved from https://doktor.se/
- Erlingsdóttir, G., & Lindholm, C. (2015). When patient empowerment encounters professional autonomy: The conflict and negotiation process of inscribing an eHealth service. *Scandinavian Journal of Public Administration*, 19(2), 27-48.

- Eyal, G., Sabatello, M., Tabb, K., Adams. R., Jones, M., Lichtenberg, F.R. ... Appelbaum, P.S. (2019). The physician-patient relationship in the age of precision medicine. *Genetics in Medicine*, *21*, 813-815. https://doi.org/10.1038/s41436-018-0286-z
- Eysenbach, G. (2001). What is e-health? *Journal of Medical Internet* Research, 3(2). https://doi.org/10.2196/jmir.3.2.e20
- Fitbit (2020, January 10th). Fitbit. Retrieved from https://www.fitbit.com/global/uk/products/trackers
- Frank, J.R. Snell, L., & Sherbino, J. (Eds.). (2015). *Can meds 2015 physician competency framework*. Ottawa: Royal College of Physicians and Surgeons of Canada.
- Foucault, M. (1986). *The History of sexuality. Volume 3: The Care of the self.* New York: Pantheon Books.
- Foucault, M. (1988). Technologies of the self. In L.H. Martin, H. Gutman & P.H. Hutton (Eds.), Technologies of the self. A seminar with Michel Foucault. (pp. 16-49). Amherst: University of Massachusetts Press.
- Fries, C.J. (2008). Governing the health of the hybrid self: Integrative medicine, neoliberalism, and the shifting biopolitics of subjectivity. *Health Sociology Review*, 17(4), 353-367. https://doi.org/10.5172/hesr.451.17.4.353
- Garmin (2020, December 19th). Garmin. Retrieved from https://buy.garmin.com/en-gB/GB/c10002-p1.html
- Gilmore, J.N. (2016). Everywear: The quantified self and wearable fitness technologies. *New Media and Society*, *18*(11), 2524-2539. https://doi.org/10.1177/1461444815588768
- Greenhalgh, T., & Swinglehurst, D. (2011). Studying technology use as social practice: The untapped potential of ethnography. *BMJ Medicine*, *9*(45). https://doi.org/10.1186/1741-7015-9-45
- Heath, I. (1995). *The mystery of general practice*. Nuffield Trust. https://www.nuffieldtrust.org.uk/research/the-mystery-of-general-practice
- Hedgecoe, A., & Martin, P. (2003) The drugs don't work: Expectations and the shaping of pharmacogenetics. *Social Studies of Science*, *33*(3), 327-364. https://doi.org/10.1177/030631270303333002
- Hjörleifsson, S., & Lea, K. (2017). *God praksis: Om medisin og etikk [Good practice: On medicine and ethics]*. Bergen: Fagbokforlaget.
- Hjörleifsson, S., & Lea, K. (2018). Mismanagement in general practice. In C. Dowrick (Ed.), *Person-centred primary care: Searching for the self.* London & New York: Routledge. https://doi.org/10.4324/9781315277073-2

- Hyman, P. (2020). The Disappearance of the primary care physical examination-losing touch. *JAMA Internal Medicine*, 180(11), 1417-1418.

 https://doi.org/10.1001/jamainternmed.2020.3546
- Jasanoff, S., & S-H, Kim. (Eds.). (2015). *Dreamscapes of modernity: Sociotechnical imaginaries and the fabrication of power*. Chicago: The University of Chicago Press. https://doi.org/10.7208/chicago/9780226276663.001.0001
- Jortveit J., Pripp A.H., Langørgen J., & Halvorsen, S. (2020). Incidence, risk factors and outcome of young patients with myocardial infarction. *Heart*, 2020(106), 1420-1426.
- Lupton, D. (1997). Consumerism, reflexivity and the medical encounter. *Social science & medicine*, 45(3), 373-381. https://doi.org/10.1016/S0277-9536(96)00353-X
- Lupton, D. (2016). The quantified self. Cambridge, UK & Malden, US: Polity.
- Lupton, D. (2017a). *Digital health: Critical and cross-disciplinary perspectives*. London & New York: Routledge. https://doi.org/10.4324/9781315648835
- Lupton, D. (2017b). Self-tracking, health and medicine. *Health Sociology Review*, *26*(1),1-5. https://doi.org/10.1080/14461242.2016.1228149
- May, C., Montori, V.M., & Mair, F.S. (2009). We need minimally disruptive medicine. British Medical Journal, 339(2803). https://doi.org/10.1136/bmj.b2803
- Medicoo. (2020, February 19th). Medicoo. Retrieved from https://www.medicoo.nl
- Mol, A. (2003). *The body multiple*. Durham, US: Duke University Press. https://doi.org/10.2307/j.ctv1220nc1
- Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. London: Taylor and Francis ltd. https://doi.org/10.4324/9780203927076
- Morgan, D.J., Dhruva, S.S., Coon, E.R., Wright, S.M., & Korenstein, D. (2019). Update on medical overuse: A review. *JAMA Internal Medicine*, *179*(11), 1568-1574. https://doi.org/10.1001/jamainternmed.2019.3842
- National Institute for Health and Care Excellence (NICE). (2020, January 12th). Type 2 diabetes in adults: management. Retrieved from: www.nice.org.uk/guidance/ng28/chapter/1-Recommendations#blood-glucose-management-2
- Pantzar, M., Ruckenstein, M., & Mustonen, V. (2017). Social rhythms of the heart. *Health Sociology Review*, 26(1), 22-37. https://doi.org/10.1080/14461242.2016.1184580
- Piras, E.M., & Miele, F. (2017). Clinical self-tracking and monitoring technologies:

 Negotiations in the ICT-mediated patient-provider relationship. *Health Sociology Review*, *26*(1), 38-53. https://doi.org/10.1080/14461242.2016.1212316

- Pols, J. (2014). Knowing patients: Turning patient knowledge into science. *Science, Technology & Human Values*, *39*(1), 73-97. https://doi.org/10.1177/0162243913504306
- Prainsack, B. (2017). *Personalized medicine: Empowered patients in the 21st century*. New York: New York University Press.
- Quantified Self. Selfknowledge through numbers. (2020, February 19th). Quantified self. Retrieved from https://quantifiedself.com/
- Reeve, J. (2010). Interpretive medicine: Supporting generalism in a changing primary care world. *Series: Occasional Papers, 2010* (88). London: Royal College of General Practitioners.
- Rich, E., & Miah, A. (2016). Mobile, wearable and ingestible health technologies: Towards a critical research agenda. *Health Sociology Review*, 26(1), 84-97. https://doi.org/10.1080/14461242.2016.1211486
- Rückenstein, M., & Schüll, N.D. (2017). The datafication of health. *Annual Review of Anthropology*, 46, 261-278. https://doi.org/10.1146/annurev-anthro-102116-041244
- Saukko, P, Farrimond, H., Evans, P.H., & Qureshi, N. (2012). Beyond beliefs: Risk assessment technologies shaping patients' experiences of heart disease prevention. *Sociology of Health and Illness*, *34*(4), 560-575. https://doi.org/10.1111/j.1467-9566.2011.01406.x
- Saukko, P. (2018). Digital health: A new medical cosmology? The case of 23andMe online genetic testing platform. *Sociology of Health and Illness, 40*(8), 1313-1326. https://doi.org/10.1111/1467-9566.12774
- Sharon, T. (2017). Self-tracking for health and the quantified self: Re-articulating autonomy, solidarity, and authenticity in an age of personalized healthcare. *Philosophy & Technology, 30*(1), 93-121. https://doi.org/10.1007/s13347-016-0215-5
- Statista (2021, January 2nd). Projected global digital health market size from 2019 to 2025. Retrieved from https://www.statista.com/statistics/1092869/global-digital-health-market-size-forecast/
- Steinberg, M. (1998). Tilting the frame: Considerations on collective action framing from a discursive turn. *Theory and Society, 27*(6), 845-872. https://doi.org/10.1023/A:1006975321345
- Stewart, M., Brown, J.B., Weston, W., McWhinney, I., McWilliam, C.L., & Freeman, T. (2013). *Patient-centered medicine: Transforming the clinical method* (3rd ed.). London: Radcliffe.
- Sulik, G.A., & Eich-Krohm, A. (2008). No longer a patient: The social construction of the medical consumer. In S. Chambre, M.A. Goldner & B.K. Rothman (Eds.), *Patients*,

- Consumers and Civil Society (p 3-28) Bingley: Emerald Publishers. https://doi.org/10.1016/S1057-6290(08)10002-X
- Swan, M. (2009). Emerging patient-driven health care models: An examination of health social networks, consumer personalized medicine and quantified self-tracking. *International Journal of Environment Research and Public Health*, 6(2), 492-525. https://doi.org/10.3390/ijerph6020492
- Swinglehurst, D., Greenhalgh, T., Myall, M., & Russel, J. (2010). Ethnographic study of ICT-supported collaborative work routines in general practice. *BMC Health Services Research*, 10, (348). https://doi.org/10.1186/1472-6963-10-348
- Swinglehurst, D. (2014). Displays of authority in the clinical consultation: A linguistic ethnographic study of the electronic patient record. *Social Science & Medicine, 118,* 17-26. https://doi.org/10.1016/j.socscimed.2014.07.045
- Swinglehurst, D. (2017). Challenges to the «self» in IT-mediated health care. In C. Dowrick (Ed.), *Person-centred primary care: Searching for the self*. London & New York: Routledge. https://doi.org/10.4324/9781315277073-3
- Swinglehurst, D., & Hjörleifsson, S. (2018). The everyday ethics of burdensome polypharmacy. *Public Policy & Aging Report, 28*(4), 113-115. https://doi.org/10.1093/ppar/pry036
- Welch, H.G., Schwartz, L., & Woloshin, S. (2011) *Overdiagnosed: Making people sick in the pursuit of health*. Boston: Beacon Press.
- Williamson, B. (2015). Algorithmic skin: Health-tracking technologies, personal analytics and the biopedagogies of digitized health and physical education. *Sport Education and Society*, *20*(1), 133-151. https://doi.org/10.1080/13573322.2014.962494