Digital health and the biopolitics of the Quantified Self

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Abstract

Recent years have witnessed an intensive growth of systems of measurement and an increasing integration of data processes into various spheres of everyday life. From smartphone apps that measure our activity and sleep, to digital devices that monitor our health and performance at the workplace, the culture of measurement is currently on the rise. Encouraged by movements such as the Quantified Self, whose motto is 'self knowledge through numbers', a growing number of people across the globe are embracing practices of self-quantification and tracking in the spirit of improving their wellbeing and productivity or charting their fitness progress. In this article, I examine the biopolitical aspects of the Quantified Self practices, exploring some of the ideologies and rationalities underlying self-tracking culture. I argue that such practices represent an instantiation of a 'biopolitics of the self' whereby the body is made amenable to management and monitoring techniques that often echo the ethos of neoliberalism. Rather than being restricted to an individualized form, self-tracking practices are also becoming part of a biosocial and communal phenomenon in which individuals are incited to share with others information about their physical activities and biodata. In exploring some examples of this data sharing culture, I critically address the extent to which the sharing of personal physical data can be seen as a 'solidaristic' act that can contribute to a larger Big Data ecosystem and inform the wider medical community and healthcare research and policy. I link this discussion to debates on 'data philanthropy', highlighting the emerging tension between philanthropic discourses of data sharing and issues of privacy. From here, I go on to discuss further ethical and political concerns, particularly in relation to data security and the marked shifts in healthcare responsibilities.

Life in the 21st century is witnessing an intensive infiltration of networked wireless technologies and digital mobile devices. Individuals and societies are becoming increasingly reliant on algorithms and data to manage all aspects of everyday activities. This digital penetration of the everyday through data and numbers is also affecting one of the most important dimensions of our existence: our health. In recent years, we have witnessed an abundance of techniques and devices that enable routine forms of digital self-tracking and health monitoring. Spurred by movements such as the Quantified Self, a growing number of people, particularly in the Western world, are embracing this culture of measuring and analysing the details of one's daily habits, activities and behaviours through digital devices, apps and online platforms. Governments across the globe are increasingly turning towards such convergent technologies to find solutions for healthcare issues in the face of growing economic and fiscal challenges. As Lupton[1] points out, with the rapid rise of wearable technologies and mobile social media, new models of healthcare are being explored and envisioned, such as mHealth, eHealth and Health 2.0, all of which rely on web tools, electronic

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forms of communication, social networking, mobile devices, and data-driven and user-centric technologies to improve the provision of healthcare. Such healthcare models also emphasize the importance of personal responsibility and initiative for health management as well as the importance of 'Big Data' generated through personal use of digital self-tracking devices.

In this article, I consider this interplay between self-tracking practices and the wider healthcare discourses and emergent strategies. I begin with an examination of the Quantified Self movement and its underpinning rationalities, followed by a discussion on the 'biopolitical' nature of this movement and its practices. This is in an attempt to explore the ideologies and techniques underlying self-tracking culture and the ways in which body and health are being subjected to regimes of knowledge production and data-driven modes of bio-power. From here I move on to examine the social and communal dimension of self-tracking, reflecting on the data sharing culture that is encouraged within the Quantified Self community and beyond. The final part of the article articulates some of the concerns pertaining to this growing trend of self-quantification and data-driven modes of health monitoring, particularly with regard to issues of privacy and data ownership as well as the marked shifts in healthcare responsibilities.

The main contributions of this article are threefold. First, the article provides a synthesized and critical overview of self-tracking practices in health and medicine, engaging with different positions vis-à-vis the Quantified Self movement. This helps to clarify the major issues relating to this subject and introduce the reader to a wide range of pertinent debates on digital health and self-tracking. Second, the article offers a useful linkage between the concept of 'data philanthropy' and debates on data sharing practices in the context of self-tracking, by way of uncovering the ideological function of data donation and its philanthropic discourses. Third, the article explores some of the tensions emerging between issues of data ownership, data sharing and privacy concerns. More specifically, the discussion illuminates how, under the increasing push for personal data sharing and corporate data philanthropy, the very notion of privacy itself is coming under threat in the way it is being implicitly cast as the opposite of 'public good', as an outdated notion that should be sacrificed for the sake of collective benefit and the ideal of solidarity. This changing rhetoric vis-à-vis privacy is indeed a key and critical outcome of the rising culture of data sharing and one that has, so far, evaded the radar of current debates and studies on the Quantified Self and health tracking practices. Ultimately this article aims to contribute to raising awareness of the possible consequences of the ever-expanding use of technologies of tracking and self-quantification, particularly with regard to issues of privacy and data security. By the same token, this article also aims to contribute to contemporary debates on the theme of biopolitics, looking at Quantified Self practices as an example of biopolitical processes and approaches to body and health.

Introduction to the Quantified Self

Rooted in the Californian tech scene, the Quantified Self represents a growing global phenomenon promoting 'a new form of wisdom'[2] whose motto is 'self knowledge through numbers'. Founded in 2007 by Gary Wolf and Kevin Kelly from *Wired* magazine, the Quantified Self movement has grown to include over 200 regular meet-up groups across 34 countries around the world. The term itself is now used to describe almost any form of self-tracking. As a buzzword in the age of so-called Big Data, this movement relates to the use of wearable digital devices and sensing technologies which enable users to record data about their everyday activities and obtain feedback in the form of graphs and illustrations. Examples of self-tracking and health monitoring devices include Fitbit Surge, Jawbone UP, Nike + Fuel, Pebble Watch, Apple Watch and a variety of smartphone applications such MyFitnessPal, Fitocracy, FitStar and Nudge. Intended to motivate users by encouraging a healthy lifestyle through daily monitoring, such devices and apps record a wide range of biometric data, health indicators and vital signs, including calories consumed, distances walked and hours slept. This is achieved through inbuilt sensors for automated data collection as well as self-reporting whereby users are required to log the food consumed and the exercises undertaken.

Whilst the future of such technologies and trends is still relatively an open-ended question, it has nonetheless become evident that we are witnessing an epistemological and ontological shift whereby our bodies and selves are increasingly being treated as 'projects' of tracking and life-logging.[3] Eric Topol[4] argues that '[f]or the first time we can digitize humans [...] in highest definition, in granular detail, and in ways that most people thought would not be possible'. He goes on to argue that the maturation of digital technologies reflects 'unprecedented super-convergence' enabled through the ubiquity of computers and smartphones, pervasive connectivity and social networking.

For the individual, the practice of tracking one's health indicators is believed to have a positive impact on one's wellbeing[5] in the way it allows the user to set daily goals, monitor health habits and identify actions that are conducive to the betterment of fitness levels and health overall.[6] Although the use of wearable tracking devices or apps does not necessarily lead to

the enhancement of exercise ability, it is argued, nonetheless, that such techniques could provide both motivation and triggers to the user (see for instance studies by Shin and Jarrahi[7] and Patel).[8] The belief is that when users are motivated by the rewarding feeling of achieving certain goals and making regular progress, they are likely to engage in more exercise or keep a healthy diet. Self-tracking devices can also function as triggers, reminding users to exercise regularly. For example, Fitbit's indicator lights up as an alarm when the device senses that the user has been sitting for too long. Apps like Waterlogged act as a 'hydration reminder' encouraging the user to increase her water consumption. These are examples of what Natasha Singer[9] calls 'the nurselike application of technology', whereby devices 'prod' the user to take action rather than just collect data. By playing the role of a 'friend' who knows the user well or the role of an authority such as a nurse or a doctor, self-tracking devices and apps aim to enhance the persuasive effect on one's behaviour. As Fogg argues, 'computing technology that assumes roles of authority will have enhanced powers of persuasion.'[10]

Of course, the notion of self-monitoring through calculation is not a new concept. Everyday metering has a long history.[11,12] Athletes have long been required to record their nutritional intake and activity, track and document their performance and progress. Women have long relied on menstrual cycles for family planning and contraception. In fact, it is argued that the idea of the first pedometer goes all the way back to Leonardo da Vinci and a sketch he made of a wheeled device which he designed to count the daily steps made by marching Roman soldiers (Figure 1).

So in a sense, the idea or desire to monitor the body and its activities is by no means new. Nevertheless, the development of new digital personalized and mobile technologies has made it easier than ever for people to collate and analyse their personal data.[13] The availability and relatively low prices of self-tracking devices and apps made it possible for the average person, especially in Western countries, to effortlessly generate various types of large statistical data and deploy quantitative methods of analysis akin to those found in science and business. As a result, the devices and techniques that were traditionally used by professionals to monitor people's health are now becoming more and more accessible to the general public, especially now that sensors are being transformed into smaller, cheaper and ultimately more manageable pieces of equipment fit for everyday use. Crawford et al.[14] identified this transition from the professional sphere to the personal one through the example of the weight scale. They argue that, over the years, the meaning and location of the scale has been gradually shifting from the doctor's office to the street and all the way to the home. So, from being an instrument of medical knowledge and expertise, the scale has eventually become part of 'a private habit and an everyday domestic discipline'.[15]

And in economic terms, measuring the body has always been a profitable industry. The personalization of biometric devices also meant an increase in consumers and users of these technologies and thereby an increase in the profit made by the manufactures of
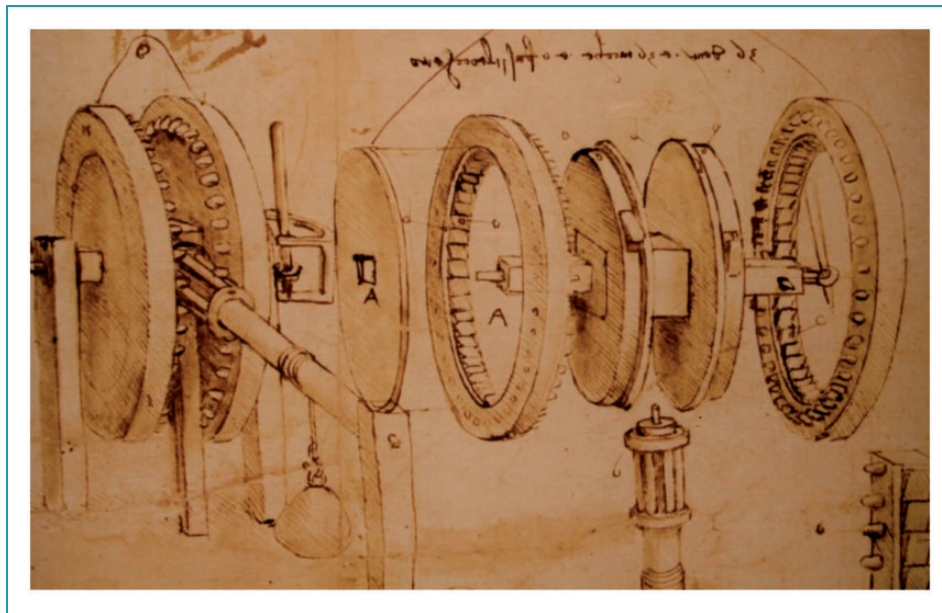

Figure 1. Sketch of Leonardo da Vinci's pedometer.

such devices. According to a recent report by BCC Research,[16] the global market for wearable self-tracking technologies has reached US$1.1bn in 2013 and nearly US$3.2bn in 2014. They expect this number to grow to US$18.8bn in 2019. The report also states that, in 2013, about 21 million individuals globally used their smartphones for self-tracking and health monitoring. The rapidly increasing market value of wearable tracking devices and apps is, indeed, indicative of the growing interest in such technologies and the notable shift towards self-quantification and performance monitoring in general.

Critics argue that this increasing focus on numbers and their potential for self-analysis and improvement is not only driven by technology alone.[17] Instead, they see it as reflective of a larger shift towards 'neoliberal' ethos of (self) governance and health management whereby individuals are increasingly expected to be in charge of their own health and wellbeing, at a time when state support for social and health programmes is in decline. Lupton,[18] for instance, argues that data-driven and technologically mediated practices of health management and self-tracking conform to a neoliberal politics which focuses on citizens' personal behaviour and self-responsibility, shifting the management of health away from institutions towards individuals themselves. Similarly, De Souza[19] suggests that 'the Quantified Self conforms to the ideal neoliberal citizen: the self-optimizing individual who voluntarily monitors, measures, regulates and collects biometric data on their own health, wellbeing and fitness; taking control of their own bodies on a minute and detailed level'. This conceptual linking of Quantified Self practices to neoliberalism is also to do with how they both incite individuals to regard themselves as 'projects', as 'mini-corporations', to put it in the words of Emily Martin,[20] that are in need of constant self-development, improvement and investment. The following statement by Gary Wolf,[21] the co-founder of the Quantified Self, does capture this project-like approach to the self:

> We use numbers when we want to tune up a car, analyze a chemical reaction, predict the outcome of an election. We use numbers to optimize an assembly line. Why not use numbers on ourselves?

The Quantified Self movement is, as such, often seen as a key illustration of a neoliberal attitude towards the self and its governance, given the way this movement encourages individuals to become rational entrepreneurs of themselves and embrace its metric culture of self-improvement whose intrinsic ideology is echoed in Kelly's argument, 'unless something can be measured, it cannot be improved'.[22] And we see this metric attitude being promoted not only in the domain of personal health and fitness management but also in other spaces including the home, leisure and work, especially given the increasingly blurred boundaries between these spheres and the gamification of life itself.[23][24][25] For instance, various companies, particularly in the United States, are now sponsoring 'wellness programmes' to encourage their employees to lead healthy lifestyles and become more active, in such a way that leisure time is becoming more and more integrated into the sphere of labour as well. Examples include a scheme by the retail company Target which offered 335,000 Fitbit devices to its US employees,[26] as well as a scheme at the oil company BP where more that 24,500 Fitbit fitness trackers were distributed to its employees in North America.[27] Health has become, as Chris Till[28] puts it, 'a corporate concern'.

Embedded within a double imperative of 'better health outcomes' and 'lower health costs',[29,30] the rationale of such corporate wellness schemes is to reduce healthcare and insurance costs and improve the productive capacity of employees. As stated by *Corporate Wellness Magazine*,[31] 'employers have their own incentives besides a healthier and more productive workforce, too. As part of the Affordable Care Act, companies can take up to 30 per cent off the cost of annual insurance premiums when employee participation is tied to corporate wellness plans.' And within these schemes, the 'good employee' is often portrayed as the healthy productive worker, the team player who does not generate medical expenses for his or her employer or insurance company;[32] again, along the lines of the neoliberal self-responsible and productive subject.

Biopolitics of the Quantified Self

Within practices of the Quantified Self and its overall philosophy, the body and its physical activities occupy central stage. The actualization of the Quantified Self's mantra of 'self knowledge through numbers' is only made possible through the vehicle of the body and the vital signs it emits and which can be read and assessed through a plethora of metric devices and techniques. Data emerging out of bodily quantification are believed to reveal some kind of 'objective truth' about the self-tracker in a way that was previously not possible through traditional techniques of self-analysis and introspection. The Quantified Self movement establishes a direct relation between the body and the self, between biology and knowledge, between technology and truth. This is obviously not the first time that technologically mediated developments attempt to establish such a strong link between body, technicity and forms of knowledge. For instance, as I argue elsewhere, the deployment of biometric identification

techniques in various fields, such as security and border control, has also redefined the relationship between body and identity. By laying claim to the idea that identity can 'objectively' be determined through the body,[33] biometrics has given the body unprecedented significance over the mind, casting it as a source of 'instant truth'.[34] This is encapsulated in the expression 'the body does not lie', an expression that became the marketing slogan of the biometrics industry.

These truth claims about the biometric body carry over into the debates on the Quantified Self. In his *New York Times* article, The data-driven life, Gary Wolf[35] begins his discussion with the assertion that humans make errors. Bemoaning the fallibility of human beings, Wolf goes on to make a case for self-tracking and data gathering as a means of surmounting human limitations and overcoming the opacity resulting from lack of information: 'If you want to replace the vagaries of intuition with something more reliable, you first need to gather data. Once you know the facts, you can live by them.' This positivistic promise of knowledge and mastery is based on the assumption that the coupling of body and data holds the key to self-discovery; that through the collection and computation of data regarding our biological functions and behaviour, we can be motivated to improve ourselves:

A profound sense of self-awareness is a by-product of the quantified experience. Trends in your behaviour become clearer, and will likely influence your future actions. Think about it... what happens when you notice you're reporting lower happiness whenever you're with your spouse; or discover that 85% of your day is spent in the office? The data doesn't lie. These realisations might be uncomfortable and force some tough decisions, but the change will be for the better.[36]

Moore and Robinson[37] argue that the Quantified Self manifesto is indicative of a wider ideology of wellness, which idealizes the rational improvement of human performance, behaviour and habits through knowledge of the body. They suggest that while self-quantification challenges the mind–body split of Cartesian dualism by casting the body as a site of knowledge, it also places the mind firmly in control. In such a dynamic, the body is regarded as a passive object of measurement that is amenable to improvement and intervention whether it likes it or not: 'The body has no agency of its own accord'.[38] Similar arguments have been made vis-à-vis biometric identification in terms of the way it instrumentalizes the body and produces forms of knowledge that are based on a 'one-way observation' and marked by a power relation.[39,40] That is not to say, however, that the body itself is always passive or reducible to an

entity that things are simply done to. Bodies can also resist and refuse to be measured in certain ways. This is manifested, for instance, in cases whereby technology 'fails' to capture certain bodies due to the subject's gender, race or disability. In relation to biometrics, for example, fingerprint scanners have routinely encountered difficulties in reliably capturing the fingerprints of Asian women because of their 'fine skin' and 'faint' fingerprint ridges, while dark-skinned users are not easily 'distinguished' by facial-scanners.[41,42,43] But whether perceived as an object or a subject, the body remains an important site of knowledge and power dynamics.

The will to knowledge is, indeed, never a neutral pursuit. For knowledge, as Francis Bacon reminds us, *is* power. And when it comes to the body, it is often a site of power as much as it is a site of knowledge, be it in terms of the regulatory systems it is subjected to (e.g. biometric identification that renders the body as 'password'; scanning technologies at the border; work-related health checks; dietary regimes) or the self-inculcated habits and practices of which self-tracking and quantification techniques are prominent examples. At the heart of the Quantified Self movement is, in fact, a desire for 'control'. As Rowse[44] argues, 'quantification provides a means for understanding the self that seems to enable a certain feeling of control. One can change a behaviour, and see a direct response in the numbers.' Bodily functions and habits can be monitored and adjusted through the feedback loops involved in self-tracking processes.

In his later writings, Michel Foucault[45,46,47,48] describes a shift in the way in which power is enacted upon the body, both the individual body and the body of the population. He argues that since the 18th century, a form of power began to permeate the social order, taking the vitality of the body and the biological existence of the population as its primary preoccupation. He calls this 'biopower'. 'Biopolitics' is the name he gives to the mechanisms, techniques, technologies and rationalities that are put at work for the purpose of managing life and the living, and governing their everyday affairs. And what differentiates biopower and biopolitics from other forms of power and politics, according to Foucault, is that they are not so much about repressive discipline and coercion but normalization and control in the name of freedom itself (although discipline and coercion could also be invoked at any time within the framework of biopolitics, but they are, arguably, not its primary feature).

Within the framework of biopolitics, control begins with the self itself, controlling its abilities, performance and productivity. And as Hille[49] argues, control of the self begins with knowledge of this self and an understanding of its vital characteristics and activities.

This argument takes us back to the heart of the Quantified Self philosophy, 'self knowledge through numbers', whereby technologically mediated quantification is regarded as the most reliable and efficient path towards 'truth' and self-improvement. 'The quantified self sits at this fulcrum between self and external control, the objectification of the self, and regulation in accordance with social norms of "health".'[50]

Practices of the Quantified Self can thus be seen as an instantiation of a 'biopolitics of the self' in which the body is made amenable to management techniques according to a set of agreed upon fitness norms, like eating five vegetables or fruits a day or walking 10,000 steps per day as recommended by the World Health Organization.[51] This recommendation of 10,000 steps a day originated in Japan in the early 1960s through research led by Yoshiro Hatano. The research estimated that walking 10,000 steps would be enough to burn around 20% of our calorie intake.[52] Currently, across all health platforms and self-tracking devices, the 10,000 steps norm is now taken as the baseline that needs to be met by users if they are to be deemed as healthy and active bio-citizens. In internalizing such norms, the self-quantifier ends up conforming to a pre-given standard of health and fitness and being normalized and (self-)assessed according to an idealized numeric identity.[53] This echoes Foucault's[54] statement on power and its manifestation in the individual's everyday life:

> Power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him.

As mentioned before, biopower and biopolitics are not so much about *explicit* coercive discipline, but follow the neoliberal modality of free choice and the promise of reward. In the case of self-tracking, it is the reward for exercise and self-regulation in line with the set norms, with the promise of a healthier life, a better-looking body, and so on. In fact, many fitness apps offer virtual 'medals' or 'badges' for achieving pre-set goals. For instance Strava, an activity-tracking website and app popular among cyclists and runners, encourages competition by awarding titles, like 'King of the Mountain', for the shortest time spent cycling up a particular hill (Figure 2). Reformulating Socrates' maxim, Strava has even raised a new philosophical enquiry: 'Is the unexamined ride worth riding?'[55]

In this way, attaching a competitive value to the use of fitness tracking technologies renders them all the more necessary for the monitoring of one's physical performance and for comparing this with the performances of other users. Again, such trends tend to address the user as a 'free individual' who can choose if, when and how to use self-tracking devices and techniques:

> The neoliberal health and productivity imperative of our present time consciously rejects terms of coercion [...] no one is forcing anyone to use these applications. Whether in Berlin, Beirut or Bogotá, the neoliberal calculation and monitoring methods of the quantified self work via the 'you could' imperative.[56]

Biosociality and the Quantified Us

> Personal data are ideally suited to a social life of sharing. You might not always have something to say, but you always have a number to report.[57]

Although the 'self' is often an over-emphasized part in the Quantified Self, it is important to point out that the management of health and fitness through self-tracking devices and apps is not restricted to the individualized form alone, but is becoming, in many ways, a socialized phenomenon and a communal trend. Wolf's above statement highlights the importance given to data sharing within the metric culture of self-quantification. Increasingly, personal self-tracking data are being integrated into social media platforms and dedicated forums that enable users of self-tracking technologies to compare data and results, share their achievements, and compete with each other. Reasons vary as to why people share data with others, but there are two main rationales that tend to underline this growing practice of biometric data sharing. First, there is the belief that social responses in the form of encouragement and acknowledgment as well as the fear of losing or visibly not meeting the set targets can be effective motivators for users to consistently engage in physical activity and pursue a healthy lifestyle. This can also introduce a pleasurable element into self-tracking in the sense that competition between users and mutual comparison of data involves a playful aspect that 'gamifies' the whole experience of tracking. Second, there is the argument that sharing data on social networks can enhance users' expertise by incorporating what Lupton[58] refers to as the 'wisdom of the crowd' through which self-trackers can draw on each other's experience and exchange constructive advice about fitness and health.

This social trend of participating in online communities, established for the purpose of sharing health related information and experience, echoes Paul Rabinow's concept of 'biosociality'.[59] This is a type of connection between individuals, which is centred

When you add a run or ride to Strava, you may be awarded "Achievements" for outstanding performances on the segments you traverse. There are a few types of Achivements.

- King/Queen of the Mountain or Course Record
- Trophy
- Medal

Crown – King/Queen of the Mountain (KOM/QOM) or Course Record (CR)

The crown represents total segment dominance! They are awarded to users who set times that slot them on top of Overall leaderboards at time of upload.
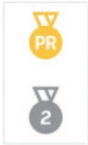
Your current All-Time KOM/QOM/CR crowns are stored in a special list on Strava for your reference. "My KOMs" or "My QOMs" is a page stored under "KOMs/CRs" or "QOMs/CRs" accessed from your Profile page on the web.

Trophy – Overall Top 10 Placement (All-Time & Annual)

A trophy is awarded when you place at the top of a segment leaderboard filtered by gender. Trophies exists for 2nd place to 10th place for all-time efforts.

Medal – Personal Top 3 Placement

Medals are awarded for your all-time best personal performances on a segment. If you clock a new best time for yourself on a segment, you'll receive a solid "PR' medal. Likewise for your second fastest and third fastest times.

Note: A user is not eligible for a PR medal until he or she has matched the segment at least two times.

Figure 2. Strava awards.

on biologically based forms of socialization. It gestures towards the interface between developments in bio-technologies, life sciences, social practices and individual and collective subjectivities.[60] The emergence of social media and other Internet enabled platforms has undoubtedly provided new opportunities for building web-based communities where individuals can share their health and disease experiences. As Hagen[61] argues, biosociality has gone 'digital' during the last years. As a result, many forms of biosocialization are becoming web-based. The sharing of one's activity and biometric data among other users is, in effect, a developing aspect of biosociality.

Fitbit website, for instance, has a community section comprising various discussion boards which allow Fitbit users to connect with each other in order to share health tips, seek advice about Fitbit products, and chat about fitness, nutrition, sleep and other health-related issues. The Forum also encourages users to share their fitness achievements on social media networks and compete with friends and colleagues. In addition and as mentioned before, through its involvement with corporate wellness programmes, Fitbit also encourages employers to institute team competitions within the workplace in order to motivate participants to achieve higher levels of fitness. Data sharing between team members and with other teams allows participants to compare results and compete further.

According to Lupton,[62] such practices of mediated 'social fitness' and 'communal tracking' tend to appeal to a deeply felt desire to be part of a community and a

need to create social bonds and a sense of solidarity. Relatedly, Tamar Sharon[63] contends that while the Quantified Self practices are often described and perceived as narcissistic and solipsistic, there is evidently an element of solidarity and communality underpinning such practices. She argues that 'the data that is generated by tracking devices is not just a tool for gaining insights about oneself but becomes a medium for connecting with others. [The] communicative and communal dimension of tracking challenges allegations of narcissism and navel-gazing.'[64] This is not only in terms of online forms of health-related biosocialization, but also with regard to the offline meetings facilitated by self-tracking communities. For example, in addition to its active social media presence on Facebook and Twitter, and its online forums which provide an ongoing platform for sharing views and experiences relating to self-tracking (quantifiedself.com), the Quantified Self community is also characterized by regular local face-to-face meetings worldwide and yearly conferences. The 'Show & Tell' presentations are a particularly important mode of communication and information sharing among the Quantified Self community. In these meetings, people perform presentations revolving around their own use of self-tracking tools, data visualization methods, health habits, etc. in the spirit of learning from each other's experiences and connecting with fellow self-quantifiers (Figure 3).

Evidently, then, there is a sense in which Quantified Self practices are not reducible to individual or individualistic forms, but embody aspects that are communal and collectivizing. However, one question needs to be raised: what *kinds* of community or forms of solidarity are at play in these practices? Sharon[65] rightly argues that self-tracking practices engender a highly 'particularistic' and 'narrow' form of solidarity as well as an exclusive type of community. For one thing, the contours of the Quantified Self community are delineated by membership that revolves around having a shared interest in common, that is, self-tracking (though one can argue that this is often the case with all forms of community), and the socio-economic advantage of having the time and financial resources to invest in acquiring and using tracking devices and engaging with the Quantified Self community, be it online or offline. Those without this common interest, means or time remain outside the contours of this community.

As of solidarity, it is a normative concept that is usually defined as a sense of unity and a collective moral relation.[66] In the context of the Quantified Self, the meaning and function of solidarity are often reduced to the act of sharing personal health data with group members and beyond (some users even choose to make their data public), and discussing experiences of illness and health related issues.

Figure 3. The Quantified Self Show & Tell Meetup in Berkeley, 2013.

In fact, shared data are increasingly regarded as a 'public good', an asset of sorts that could potentially be beneficial not only to the individual but to society at large. In such a context, solidarity becomes almost synonymous with data sharing and information giving.

One example worth noting here is the website Patients Like Me, an online network that allows its members to enter a variety of data relating to their health condition and comparison of users' treatments, symptoms and experiences.[67,68] Users of this site are also encouraged to make their health data available for medical research. The platform also offers its members the opportunity to enrol into clinical trials relating to the development of new pharmaceuticals.[69]

In 2014, Patients Like Me launched a campaign under the name 'Data for Good' in order to promote the sharing of personal health information to advance research in the medical and pharmaceutical fields. Michael Evers, the Executive Vice President of Marketing and Patient Advocacy at Patients Like Me, describes the campaign as 'our way of tipping our hats to the massive amounts of data that our members have shared to date. It's also meant to inspire more people to contribute their experiences to accelerate research'.[70] The campaign followed the result of a survey conducted by the Institute of Medicine with users of Patients Like Me in which it was reported that '94% of U.S. adult social media users with a medical condition agree with sharing their health data to help patients like them and should be used to improve the care of future patients.'[71] As pointed out by Rhodes,[72] individuals who are willing to share their self-tracking data for research believe that their data will contribute to advancing knowledge in fields relating to healthcare, social and behavioural science, bioinformatics, and so on.

In a series of public announcements videos,[73] Patients Like Me continued to encourage a user/ patient-centric approach to medicine and healthcare emphasizing the importance of 'donating' health data as well as countering the 'culture of distrust' that historically marked public attitudes towards pharmaceutical industries.[74] Patients Like Me campaign can be seen as part of an emerging trend that has been gaining momentum in recent years, namely 'data philanthropy'. The term was first introduced by the United Nations Global Pulse (UNGP), set up in 2009 as a collaborative initiative devoted to exploring innovative ways of harnessing the potential of different Big Data sources within various fields, including health and wellness. At the heart of this initiative is the belief that data sharing is a positive act that can be beneficial to the public. The term philanthropy itself helps reinforce this belief and emphasizes the public good dimension of the initiative and its philosophy of data donation.

The UNGP[75] describes data philanthropy as a form of partnership between private and public entities which centres around the principle of data sharing (of both user-generated content and mined data) in the name of public benefit and the enhancement of policy action: 'At Global Pulse our strategy has been to form strategic partnerships with leading organizations that have the data, technology, and human expertise to learn how to do [data] analysis.'[76]

In the context of health, data philanthropy is now promoted as playing an important role in the advancement of medicine and healthcare. Health researchers are using data obtained from social media platforms, mobile devices, blogs, and shared self-tracking data to detect diseases and track their outbreak, profile patients and identify risk categories, analyse clinical trials and so on.[77] Increasingly, government organizations, pharmaceutical and insurance companies, healthcare providers, employers, medical technology industries and developers of self-tracking devices are exploring ways of exploiting personal self-tracking data and encouraging the embrace of a data sharing culture.

Data collection through wearable devices and self-tracking practices is receiving great attention within health related sectors. Such practices are increasingly being looked up to as a means of realizing the aspirations of participatory, preventative and mobile healthcare models. This is insofar as self-tracking practices can enable the capturing of quantifiable health data that can feed into decision-making vis-à-vis one's lifestyle, diet options, exercise activities, performance and habits, while comparing these with the wider population. According to Rhodes,[78] 'the immediate benefit of self-tracking data is that it can provide better measures of everyday behavior and lifestyle, filling the gaps in more traditional clinical data collection and presenting a more complete picture of health'. What this offers at the broader level of public healthcare is the promise to enhance risk management and analysis regarding health and illness. Self-tracking practices also promise to stimulate a shift from an exclusive dependence on health professionals towards a participatory model of health management, and to move individual, societal and institutional mind-sets from 'an exclusive focus on the cure of disease' towards 'personalized preventive health maintenance'.[79]

The private health insurance industry is also exploring possible applications of self-tracking data for risk mapping and for setting premiums. Companies like UnitedHealthcare are in the process of developing a new fitness app that offers financial incentives for users who maintain a healthy lifestyle.[80] Pilot programmes are underway to offer special conditions or reduced insurance rates for users who share their self-tracking data and graphs as proof of healthy and

responsible behaviour.[81] The purpose behind these schemes is to increase individual responsibility towards one's health while also enabling analytical forecasts and projections based on the everyday habits of users, on their exercise routines and diet, in order to make targeted policies to different customers.

The passage from 'small data' (individual self-tracking data) to Big Data is also part of the discussions and plans concerning how personal data can usefully contribute to shared collective health goals.[82] Both the public and the private health sectors are interested in how self-tracking data generated by individual users can feed into a larger Big Data ecosystem. The belief is that when ensembles of individuals' data are combined, a collective social picture can be drawn, that of the 'population', its health, finances, productivity and so on. It is about a move from the biopolitics of the self to the biopolitics of the population, from the micro to the macro level, from the Quantified Self to what Jordan and Pfarr[83] call the 'Quantified Us', all for the purpose of prediction, control, risk analysis and decision making at a larger scale. The following statement articulates some of the discourses mobilized in support of the harvesting and sharing of self-tracking data and linking these to bigger data ecologies:

> Imagine a future where self-tracking harnesses the power of a whole population's data to identify patterns and make meaningful recommendations about what we should do next. Imagine a future where we can fluidly move between our own data and the data of the collective to gain insights on how best to live the life we desire, and where we decide what privacy we give up, because we control the benefit it brings us?[84]

Jordan and Pfarr describe the Quantified Us as the space between small data and Big Data, and between the Quantified Self and the crowd. The term itself designates groups of people who share similar health goals and conditions, characteristics or behaviours, biometric features or environmental factors. Through the Quantified Us, the authors argue, the collective and individual relevance of self-tracking practices could be heightened, as quantified data could uncover insights about networked individuals and populations, and lead to more effective crowd-sourced health collaborations. For this, there is a call for new biosocialities to be formed together with stronger alliances between relevant public and private entities.[85] The Quantified Self community is already exploring such a process.

Two years ago, with the support of the Wood Johnson Foundation, leaders of the Quantified Self started organizing a yearly event under the name 'Quantified Self Public Health Symposium' with the aim to bring together researchers, policy makers, medical experts, users and developers to debate and explore the benefits of the Quantified Self methods for the field of public health. Casting itself as a mediator between these stakeholders, the Quantified Self group aims, through these yearly symposiums, to achieve what it sees as 'a common goal' of advancing 'the cause of access to data for personal and public benefit'.[86] In their report on the Quantified Self Public Health Symposium 2014, Wolf and Ramirez[87] argue that

> Self-collected data will change public health research because it ties science to the personal context in which the data originates. Public health research will change self-tracking practices by connecting personal questions to civic concerns and by offering novel techniques of analysis and understanding [...] To us, improving access to self-collected data for personal and public benefit means broadly advancing this practice.

Articulating this issue in terms of a mutually beneficial relation between the individual and civic society, between public and private organizations contributes to the legitimization of data collection and sharing practices and positioning these at the heart of the debates on the future of healthcare. Wolf and Ramirez,[88] admittedly, recognize the monopolizing role of private companies in controlling access to personal data flows and the commercial dimension of their operations.

Indeed, the question of data ownership is one of the most contentious issues in the debates concerning Quantified Self practices. The concept of ownership itself implies 'a level of control over the fate of data'.[89] As it stands at the moment, the majority of terms of use agreements in relation to personal data technologies typically state that 'the company providing the technology either fully owns or has full and complete rights to the data, including the right to repackage and sell datasets to others as long as they have been anonymized.'[90] Some device manufacturers sell data back to users by charging them a monthly fee while also selling data to third parties.[91] Fitbit, for instance, used to charge users US$50 a year to download their records.[92] Within its legal policy, Fitbit states that de-identified data 'may be used to inform the health community about trends; for marketing and promotional use; or for sale to interested audiences.'[93]

Herein lies the tension between the concept of data philanthropy, data ownership and the commercial use of data, a tension that will continue to pose a challenge for health professionals, researchers, policy makers, users and manufacturers alike, while also having implications vis-à-vis privacy issues. Reflecting on such

issues, Kirkpatrick,[94] the Director of the UNGP, argues that debates on the sharing and use of data have devolved into 'an existential struggle between two camps: one which believes that privacy is dead and profit is king, and one which fears that any reuse of data beyond the original purpose for which it was collected is a potential threat to privacy and civil liberties.' To this end, Kirkpatrick calls for a change in mind-set to allow for data to be safely and responsibly treated as 'a raw public good' rather than a private property. 'For this to happen, data philanthropy has to become a private sector priority', Kirkpatrick adds.

In a similar vein, the legal scholar Jane Yakowitz[95] warns that if we do not relinquish the dominating popular view of personal data as property and reframe it instead as a public asset that needs to be shared as well as protected, we run the risk of unduly obstructing research and innovation. Such arguments are reminiscent of the debates on the 'solidaristic' dimension of data sharing and its attendant rhetoric of 'public good' discussed earlier. While these arguments are couched in philanthropic terms, they are also in danger of pitting so-called data philanthropist *against* privacy advocates. It is not hard to imagine how, in such a context, caring about privacy might start being increasingly perceived as a selfish and anti-solidaristic act or, at least, as 'a quaint notion of a bygone era'.[96] And 'when a few have the ability and incentive to disclose, all may ultimately be forced to do so', as Peppet[97] argues.

In fact, individual privacy is increasingly seen as standing in tension with public interest and robbing communities of valuable information and knowledge. The discourse of 'privacy versus security', often found in the post-9/11 political discourse justifying surveillance practices in the name of protecting the nation, is now also seeping into the health sector and medical research under the banner of 'privacy versus public good'. One only has to look at the titles of some articles and scientific studies in the field of health research[98,99] to realize how privacy is often thought of as a normative individualistic concept that is inherently in opposition to the collective good. Privacy is often believed to be of value to the individual only rather than to society as a whole. What follows is that, in the name of altruism and public good, individuals and organizations are subtly being encouraged to prioritize sharing and contributing over maintaining privacy. However, such binary thinking about privacy is rather reductionist and simplistic if not even dangerous. First, it reinforces, implicitly at least, the misleading assumption that individuals wishing to keep their data private are either selfish and desire privacy because they are not interested in helping others, or bad and desire privacy to hide negative acts and information. Second, this binary thinking is also underlined by the misconception that privacy is a purely individual right and does not extend to society at large. Yet, privacy has a crucial social function. It is not about the individual versus society but constitutes a key element of a 'healthy' functioning interface between the individual and society.[100] Privacy enables the management of the needed social boundaries and interactions, the maintenance of freedom of thought, speech and political activity, the opportunity to change, grow and reinvent oneself, the ability to set limits on the power of governments and companies, and to calibrate the levels of trust and intimacy we want to share with others. These are important matters that are by no means confined to the individual interest alone but carry a social value that is relevant to group welfare and to the overall functioning of society. *Everyone* needs 'a room of one's own', to put it in the words of Virginia Woolf, and privacy *is* a public good in itself, as Fairfield and Engel strongly assert.[101]

In societies where there is an increasing privatization of health services, personal privacy and the protection of one's health data are all the more important. For without these, the outcome may end up being a total transfer of power from individuals and communities to organizations and industries, such as insurance and pharmaceutical companies, whose ultimate aim might not so much be about the public good after all, but profitmaking. To care about privacy and personal data, in this sense, is the opposite of selfishness (see also Bernal[102]). And when it comes to the issue of self-tracking data, the regulatory gaps together with the commercial aspect of self-tracking industry do raise indeed significant privacy concerns that cannot be ignored.

What follows is a further reflection on related ethical issues pertaining to self-tracking practices and data.

Ethical issues: security, privacy and responsibility

The idealized vision of participatory and preventative health models does, in fact, need everyone to share their self-tracking data to feed the overall social Big Data. It requires the involvement of multiple entities, including the general public, healthcare institutions, the government, research institutions, relevant health professionals, third-party service providers, wearable device vendors and so on. Within such an informational ecosystem, data could be easily leaked, sold, used and misused by either one or several of the parties involved. For instance, a recent experimental research conducted by Symantec[103] found several security risks in a large number of self-tracking apps and devices. One of the most significant findings was that 'all of the wearable activity-tracking devices examined, including those from leading brands, are vulnerable to location

Figure 4. Symantec Blueberry Pi scanning device, 2014.

tracking.' Portable Bluetooth scanning devices built by Symantec researchers were taken out to busy public spaces and athletic events (Figure 4). These devices, which can be built at a cost of US$75 each and with basic IT skills, were able to easily track the location of individuals carrying the self-tracking devices encountered. Symantec also found vulnerabilities in the way personal data are stored and managed. By merely scanning the airwaves for signals emitted from self-tracking devices, Symantec scanners were able to hone in and read the stored data.[104] Twenty per cent of the self-tracking services examined by Symantec were found to be transmitting usernames and passwords in clear text without any encryption, leaving them vulnerable to unauthorized use and interception. Symantec also found that a staggering 52% of the apps and devices examined did not have privacy policies. For the rest, many did not provide any clear information on how the generated data would be kept private. Such alarming findings do call for more effective data security mechanisms and clearer regulatory frameworks.

At the technical level, the safeguarding of data requires better information management systems, especially when the majority of these personal tracking data are stored in the 'cloud', which might not always be sufficiently secure or fully hack-proof. Access to such data needs to be strictly controlled through different permission levels to ensure the privacy and security of personal information. In terms of regulation, relevant laws need to be updated and developed further to keep up with the rapid growth and deployment of self-tracking technologies, and reflect their nuanced and multifaceted implications. Policies adopted by tracking companies need to be made clearer and less ambiguous. Fitbit's privacy policy,[105] for example, reveals some grey areas regarding the company's approach to personal data sharing and selling. On the one hand, the policy states that 'We will never sell your data, and will only share personally identifiable data when you direct us to'. However, in another paragraph, it is stated that 'We only share data about you when it is necessary to provide our services, when the data is de-identified and aggregated, or when you direct us to share it.' Here, the term 'necessary' remains ambiguous and open to many interpretations. It is not clear under which 'circumstances' Fitbit deems data sharing as necessary for providing its services. Furthermore, the policy also contains the following clause:[106]

We will only share PII [Personally Identifiable Information] data under the following circumstances:

- With companies that are contractually engaged in providing us with services like order fulfillment, email management and credit card processing. These companies are obligated by contract to safeguard any PII they receive from us.
- If we believe, after due consideration, that doing so is reasonably necessary to comply with a law, regulation, or valid legal process. If we are going to release your data, we will do our best to provide you with notice in advance by email, unless we are prohibited by a court order from doing so or where the request or legal process is directly related to a regulatory investigation. In the latter case, we will ensure user information we disclosed is treated as confidential.
- If it is necessary in connection with the sale, merger, bankruptcy, sale of assets or reorganization of our company, your PII can be sold or transferred as part of that transaction as permitted by law. The promises in this Privacy Policy will apply to your data as transferred to the new entity.

One tangible example has been a legal case in Canada in 2014, which saw Fitbit data being used in the courtroom to assess the relative fitness of a person making an injury claim.[107] Another example relates to the case of a woman in the United States who claimed to have been attacked and sexually assaulted by an intruder while she was asleep. After accessing and analysing data from her Fitbit device, the police showed that she was awake and walking around at the time she claimed to have been attacked. So, instead of being regarded as the victim, she was charged with making a false report to law enforcement and tampering with evidence.[108] Tellingly and in response to this case, the Lancaster county district attorney in Florida asserted that 'when we have technology like Fitbit we're going to take advantage of that'.[109] Cases like these demonstrate how self-tracking data can stand as *a witness against oneself* and in ways that reveal the functional creep of self-tracking practices beyond their initial intended purpose of personal fitness and health monitoring.

Proponents of data sharing often invoke 'de-identification' of data as a technique of privacy control and a way to protect anonymity. De-identification is usually defined as the process through which a person's identity is prevented from being connected with information, while still being able to conduct and gain the benefits of correlative analysis. Yet, there have been various cases where 're-identification' occurred. As cited in DataFloq,[110] examples include the re-identification of Massachusetts Governor William Weld from anonymized health information,[111] the re-identification of individuals from AOL search data leak in 2006, and the cross-correlation of anonymous NetFlix users with Internet Movie Database public reviewers.[112] And even if de-identification does not lead to breaches in personal privacy, it does not mean that individuals would want their data to feed into aggregate datasets and processes to which they have not consented in the first place. Moreover, and as DataFloq[113] argues, the focus on identifiability as 'the sole source of privacy violations ignores an entire class of potential harm. Not all privacy violations target the individual and some may affect society in ways that the individual does not wish to participate [...;] Even if my individual contribution is de minimus, the collective contribution of all the people data may have an affect on society that I don't want to participate in.'

For instance, one may not wish to contribute to processes of biopolitical categorizations that are enabled through Big Data practices. Categories, as we know, are by no means neutral or apolitical. Categories can be used to differentiate and discriminate, as is the case, for instance, with price discrimination on the basis of demographic or geographical information. Foucault argued that biopolitical techniques of governance often divide groups and populations into categories and according to constructed criteria of normality and abnormality, health and illness and so on. This enables the systematic ordering, profiling and classification of individuals and groups into pattern types and distinct categories for the purpose of risk analysis and management. In the context of healthcare and health insurance, risk-based and data-driven management techniques that rely on practices of categorization may lead to reinforcing further forms of inclusion and exclusion whereby some citizens are provided access to public and healthcare services while others are denied.

It is therefore crucial to be attentive to the ways in which Big Data 'translates in the lives of people',[114] and to how data-driven categories affect the material experiences of individuals and groups and shape their life chances.[115] Data, whether de-identified or otherwise, individual or aggregate, are by no means disembodied or immaterial. Neither are they objective nor agnostic. Data are deeply embedded in cultural, social, political and economic settings that reflect the implicit values and agendas of their contexts. As Dwork and Mulligan[116] rightly argue:

> Both the datasets and the algorithms reflect choices, among others, about data, connections, inferences, interpretation, and thresholds for inclusion that advance a specific purpose [...] classification systems are neither neutral nor objective, but are biased toward their purposes [...] The urge to classify is human. The lever of big data, however, brings ubiquitous classification, demanding greater attention to the values embedded and reflected in classifications, and the roles they play in shaping public and private life.

Moreover, shifts in health initiatives also mean a shift of responsibilities. As mentioned before, self-tracking practices and the various data they produce are increasingly looked up to as a means of achieving the ideals of preventative, participatory and personalized models of healthcare, envisioned as a solution to the economic challenges facing current public healthcare systems. Within such models and amid the neoliberal rhetoric of freedom and choice, individuals are expected to play a central role in the management of their own health, wellbeing and illness prevention, while the dominant role of traditional healthcare institutions is expected to shrink. The increased individual health awareness together with the rising self-tracking culture are undoubtedly contributing to shifting health responsibility from the state and medical institutions to a privatized and individualized responsibility frame: 'self-tracking apps devolve an increasingly intricate and detailed level of responsibility for one's health status and sense of wellbeing onto the individual who, in turn, eagerly monitors herself; reflected in that tiny, shiny screen'.[117] But whether personal efforts and digital devices can replace expert and professional knowledge in medicine and healthcare is something that certainly needs careful consideration and thorough assessment.

To conclude, it is evident that the Quantified Self phenomenon and self-tracking culture in general are bringing about new possibilities, advantages and benefits vis-à-vis health related issues, especially in terms of helping to promote a sense of health awareness and an autonomous approach to health management. The interest in apps, devices and platforms that enable data capturing and the monitoring of everyday activities, behaviours and habits is set to increase at the individual, collective and institutional level, as these technologies become more and more embedded in our everyday products and interwoven into our daily routines and practices. At the same time, such developments are also raising many important socio-political, ontological and

ethical concerns that have yet to receive the sustained attention they deserve. In this paper, I addressed some of these concerns, focusing on issues of privacy, security and data ownership, particularly in light of the sharing culture and the context of data philanthropy whose discourses and practices are currently on the rise.

In the passage from individual data to communal data, from the Quantified Self to the 'Quantified Us', from the 'biopolitics of the self' to the biopolitics of the population, issues of privacy, data ownership and security become all the more important, especially given the increasing commercial and governmental interest in self-tracking data. One notable issue raised in this paper is to do with the changing attitudes towards privacy itself. Increasingly, privacy is perceived as being too individualistic, too narrow and too implicated in outdated liberal assumptions about individual rights and discourses of subjectivity. Consequently, the concept of privacy is becoming cast more and more as the opposite of collective good and as a hindrance to realizing the ideal and assumed benefits of open knowledge, open data and transparent information. In response, I argued that such attitudes are based on a misconception of what privacy entails and misrecognition of its value to society as a whole. I also emphasized the need for better security infrastructure and more adequate regulatory frameworks for protecting individual and communal self-tracking data. With the rapid spread of smart wearable technologies and their infiltration of everyday life, it is important that theorists, critics and users of such technologies become more vigilant about the kind of future that is being designed through the normalization of self-tracking practices and the datafication of life itself.

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