

## I Run, You Run, We Run

### A Philosophical Approach to Health and Fitness Apps

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#### 11.1 Introduction

Since the introduction of the Apple iPhone in 2007 and the App Store that accompanies it, millions of people have downloaded and used health and fitness apps on iPhones, Android phones and other smartphones. In 2016, 102.4 million smartwatches and fitness trackers shipped. Fitbit alone shipped 22.5 million devices in that year.<sup>1</sup> Health and fitness apps, often used in combination with wearable sensing technologies, primarily track physical fitness, sleep, diet, smoking and stress.<sup>2</sup> The predominantly healthy users of these apps aim to acquire knowledge about their behaviour and states in order to maintain or improve their daily functioning and well-being.

How to understand this phenomenon of self-tracking? Are these technologies tools to increase self-knowledge and to empower individuals to better take care of themselves? This position is taken by the global Quantified Self (QS) movement, which understands self-tracking or 'life-logging' practices as a way to acquire 'self-knowledge through numbers'.<sup>3</sup> The Socratic phrase 'Know Thyself' is used to argue that quantified knowledge of the self is the starting point to reach and maintain a healthy and good life.<sup>4</sup> Self-tracking is thus a personalised type of

<sup>1</sup> Dan Graziano, 'Fitbit sold more wearables in 2016 than Apple and Samsung combined', *CNET*, 2 March 2017, available at [www.cnet.com/news/fitbit-sold-more-wearables-in-2016-than-apple-and-samsung-combined](http://www.cnet.com/news/fitbit-sold-more-wearables-in-2016-than-apple-and-samsung-combined) (accessed 2 February 2018).

<sup>2</sup> Eun Kyong Choe, Nicole B. Lee, Bongshin Lee, et al., 'Understanding quantified selfers' practices in collecting and exploring personal data' (2014) *Conference on Human Factors in Computing Systems – Proceedings* 1143–52.

<sup>3</sup> Deborah Lupton, 'M-health and health promotion: the digital cyborg and surveillance society' (2012) 10(3) *Social Theory & Health* 229–44. See also: [quantifiedself.com](http://quantifiedself.com).

<sup>4</sup> Gary Wolf's talk on the Quantified Self at TED@Cannes, [www.ted.com/talks/gary\\_wolf\\_the\\_quantified\\_self](http://www.ted.com/talks/gary_wolf_the_quantified_self).

'primary prevention', that is, prevention of disease, injury or early death before it ever occurs.

However, self-tracking technologies can also be understood as disciplinary instruments that subject (groups of) individuals to disciplinary regimes in order to reach the highest level of health and well-being for both the individual and the population at large. This critical stance is taken by sociologists, science and technology and human-computer interaction scholars who analyse the health and illness norms inscribed in self-sensing and self-monitoring technologies.<sup>5</sup> Self-tracking is here understood as both a personal and a collective type of primary preventive health. Commercial rather than public goods seem, however, to rule these disciplinary regimes.

In this chapter, we put these two ways of understanding self-tracking technologies into a broader philosophical context. We will first show that understanding the use of these technologies as a form of self-knowledge and self-empowerment is part of a more general discourse of what Donna Dickenson calls *Me Medicine*, a style of medicine centred on the individual's personal health and well-being. Second, we will show that understanding self-tracking technologies as disciplinary instruments is part of a broader discourse that criticises the so-called 'biopolitical' societal development in which populations and individuals are submitted to health norms that support economic and political goals.<sup>6</sup> Although these disciplinary regimes operate at both the individual (Me) and collective level (We), corporate interests rather than common goods dominate the market of health and fitness apps.

Though it is tempting to be either enthusiastic or to remain critical of self-tracking technologies for health and fitness, we will examine approaches in philosophy that allow us to offer a third alternative. Starting from the assumption that the view of mankind from which

<sup>5</sup> Deborah Lupton, 'Self-tracking cultures: towards a sociology of personal informatics' (2014) *Proceedings of the 26th Australian Computer-Human Interaction Conference on Designing Futures: the Future of Design* 77–86; Vera Khovanskaya, Eric P. S. Baumer, Dan Cosley et al., 'Everybody knows what you're doing: a critical design approach to personal informatics' (2013) *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* 3403–12; Stephen Purpura, Victoria Schwanda, Kaiton Williams, 'Fit4life: the design of a persuasive technology promoting healthy behaviour and ideal weight' (2011) *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* 423–32.

<sup>6</sup> Michel Foucault, *The Will to Knowledge: The History of Sexuality*, Vol. 1 (London: Penguin, 1976); Michel Foucault, *Discipline and Punish: The Birth of the Prison* (London: Penguin, 1977); Nikolas Rose, *The Politics of Life Itself*.



one designs has a bearing on the design itself and on the constellations of humans and technologies that one brings about, we argue for a design of self-tracking technologies that is predominantly informed by notions of We Medicine. In this perspective, the users' responsibility for primary prevention is not limited to their own selves, but encompasses broader common interests and goods related to health and fitness.

### 11.2 Me Medicine and Health Apps

In her thought-provoking book *Me Medicine vs We Medicine*, Donna Dickenson analyses how publicly targeted healthcare has increasingly been replaced by personalised forms of medicine. Direct-to-consumer genetic testing, personal tailored drug regimes, personalised pharmacogenetics, private umbilical cord blood banking and enhancement technologies are examples of an ever more individualised healthcare. What these technologies have in common is an underlying assumption that 'individual' is better than 'social' and that a 'true revolution' is going on in medicine to make it more individualised.<sup>7</sup> What makes Me Medicine attractive to patients, physicians, multinational firms, researchers and even 'presidents of the United States',<sup>8</sup> is that it goes beyond the 'one size fits all' model for patients. What could be more appealing than physicians being able to make the most effective medical decisions for individual patients?

In her philosophical exploration of why people are tempted to buy into personalised medicine, Dickenson discerns four possible reasons: threat and promise; narcissism; corporate interests and political neoliberalism; and the sacredness of personal choice. Dickenson draws on a range of technologies, such as private umbilical cord banking, direct-to-consumer genetic testing and enhancement technologies, to illustrate these approaches to understanding Me Medicine. These technologies are not the only ones that exemplify the shift towards Me Medicine. We argue that activity trackers and accompanying health and fitness apps also embody the reasons that people might be tempted to subscribe to personalised medicine.

*Threat and promise.* The rise of individualised healthcare is inspired not only by fear of threats such as pollution, toxins, the Zika virus and other contagious diseases, but also by financial or political crises that make it difficult to find insurance for healthcare. The anxiety that there

will be no one to help you when you fall ill encourages people to find out all they can about their personal health risks and to minimise the chance of illness. In this perspective, do-it-yourself diagnostic and therapeutic technologies appear to be the best means to prevent diseases and to promote health and fitness.

Health and fitness apps play on the promise to tackle these threats. Optimism and promises about a better personal life seem better strategies to seduce potential users than the pessimistic message of threats.<sup>9</sup> The apps aim to help their users mitigate the risk of a sedentary life by prompting them to be active frequently. For example, one of the latest versions of the Fitbit Charge, the Charge 2, sends users reminders to move, encouraging users to take 250 steps every hour. Fitbit calculates users' 'active minutes' and refers to Centers for Disease Control's recommendations on how much physical activity adults need.<sup>10</sup> Among the recommendations is a minimum amount of activity that adults need. While this does not explicitly indicate a threat, it can leave users feeling uncomfortable if they do not move enough to meet these recommendations.

*Narcissism.* In a celebrity culture, every person seems to be as newsworthy as celebrities. Each detail of one's life and one's body can be the stuff of drama. Social media provides individuals with the means to express themselves by showing their performances, daily activities, workouts or outputs. Self-expression, self-admiration and self-centred behaviour is stimulated by the likes of digital 'friends'. This sharing on social media platforms could be seen as a type of social bonding, but it is often reached through group closure. People who are 'not like us' are excluded. More in general, the practice of increasing social capital through group closure, which has become ever more common in the USA, might be one of the explanations why there is more 'Me'ness in today's medicine and social policy.<sup>11</sup>

Popular commercial self-tracking technologies invite users to indulge in narcissistic activities. Users are encouraged to track every step, every meal (or snack) they eat and even every hour of sleep. Statistics are often

<sup>9</sup> Similarly, the brand for companies selling direct-to-consumer personalised genetic testing is promise rather than threat. See Dickenson, *Me Medicine vs We Medicine*, p. 55.

<sup>10</sup> Fitbit, *What are Active Minutes*, available at: [help.fitbit.com/articles/en\\_US/Help\\_article/1379](http://help.fitbit.com/articles/en_US/Help_article/1379) (accessed 2 February 2018; Centers for Disease Control and Prevention, *Physical Activity*, available at: [www.cdc.gov/physicalactivity/basics/adults/index.htm](http://www.cdc.gov/physicalactivity/basics/adults/index.htm) (accessed 2 February 2018).

<sup>11</sup> Dickenson, *Me Medicine vs We Medicine*, p. 17.

<sup>7</sup> Dickenson, *Me Medicine vs We Medicine*, p. 4. <sup>8</sup> Ibid.



presented back to the user in dashboards, where graph bars and histograms display the past week of steps, active minutes, meals and sleep, for the user to peruse in an attempt to gain 'self-knowledge'. On those activities where a user has exceeded some personal goal, the visualisation of that activity might contain a green element (to indicate goodness) or a star (to indicate achievement). In some cases, a user will earn a badge (e.g. the Trail Shoe badge in Fitbit, which indicates 30,000 steps) to display on her personal profile. Users are encouraged to share these achievements on social media.

*Corporate interests and political neoliberalism.* Personalised medicine has coincided with the growing dominance of a neoliberal political ideology that aims to limit the state's involvement in healthcare and public wealth and increases the involvement of private corporations. The state is believed to be harmful to free markets, whereas the free market is seen as the 'true creator of wealth'.<sup>12</sup> This dominance of free market economics has affected science and medicine as well: private capital has entered a wide range of medical and scientific activities. Profits can be gained in personalised diagnostic tests, personalised treatments, personalised drug regimens and personalised information.

The immense growth of the personalised health and fitness apps market is a further sign of neoliberalism's influence in Me Medicine. These apps emphasise that, through self-tracking, one can adjust one's behaviour to optimise one's well-being and productivity, echoing the neoliberal focus on self-responsibility.<sup>13</sup> Furthermore, the apps portray health and fitness as things that can be shaped in the first place and should be, supported by consumer products.<sup>14</sup>

Commercial health apps also explicitly play to corporate interests, by offering products for corporations. FitBit, for example, introduced the programme 'Group Health', which allows clients to 'keep employees happy, healthy and engaged by creating an effective wellness program with Fitbit'.<sup>15</sup> This Group Health programme aims to 'improve employee health status' and 'create a culture of well-being'.<sup>16</sup> These are typically among the aims of public health, but here we see these functions shift towards private organisations (facilitated by Fitbit). Essentially, this aligns with policies of 'rolling back the state' and involvement of private

<sup>12</sup> Ibid., p. 20. <sup>13</sup> E.g. Lupton, 'Self-tracking cultures'.

<sup>14</sup> Brad Millington, 'Smartphone apps and the mobile privatization of health and fitness' (2014) 31 *Critical Studies in Media Communication* 479–93.

<sup>15</sup> Fitbit, *Health Solutions*, [www.fitbit.com/nl/group-health](http://www.fitbit.com/nl/group-health) (accessed 2 February 2018).

<sup>16</sup> Ibid.

organisations in key governmental functions (i.e. public health) – policies Dickenson describes as neoliberalism: 'We the people' has become 'We the market'.<sup>17</sup>

Moreover, the benefits of Fitbit's Group Health programme are framed in terms of the corporate benefits of employee well-being, e.g. '[r]esearch shows that wellness programs can have big benefits for your business'; '[c]ompanies with worksite wellness programs experience an 8% increase in employee productivity';<sup>18</sup> and 'Decrease healthcare costs – CDW Healthcare reports wearable technology could reduce hospital costs by as much as 16% over the course of 5 years'.<sup>19</sup> Inserting these types of interests into the function of health promotion can be seen as a downplaying the notion of the public good.

*The sacredness of individual choice.* Autonomy, personal choice and self-ownership have become the paramount values both in medical ethics and in society as a whole. Me Medicine relies heavily on the rhetoric of unlimited personal choice. In light of the commodification of medicine, this focus on autonomy and individual choice has transformed into a sacredness of the *consumers'* personal choice, self-engagement and self-care. Communitarian forms of medicine are challenged, because they limit individual choice.

The emphasis on individual choice is clearly prevalent in discourses on digital technology-driven healthcare. As the sociologist Deborah Lupton has observed, patients and lay-persons have become 'participants' who are deliberately and actively involved in self-care. In her view, these discourses also represent the latest version of patient consumerism:

In contemporary discussions of patient consumerism, the discourse of patient engagement is brought together with that of digital medicine to construct the figure of what I term 'the digitally engaged patient' when lay people are advised that they should use digital technologies as part of patient engagement practices.<sup>20</sup>

Health and fitness apps fit into this focus on individual choice. Wearable activity trackers and accompanying apps, such as FitBit, Jawbone UP and Moov NOW, embrace individual choice and self-engagement even

<sup>17</sup> Dickenson, *Me Medicine vs We Medicine*, p. 185. She draws this phrase from Thomas Frank's book *Pity the Billionaire* (2012).

<sup>18</sup> Fitbit, *Health Solutions*, [www.fitbit.com/nl/group-health](http://www.fitbit.com/nl/group-health) (accessed 2 February 2018).

<sup>19</sup> Fitbit, *Fitbit for Corporate Wellness*, [www.fitbit.com/content/assets/group-health/FitbitWellness\\_InfoSheet.pdf](http://www.fitbit.com/content/assets/group-health/FitbitWellness_InfoSheet.pdf) (accessed 2 February 2018).

<sup>20</sup> Deborah Lupton, 'The digitally engaged patient: Self-monitoring and self-care in the digital health era' (2013) 11(3) *Social Theory & Health* 256–70, p. 258.



before users purchase an activity tracker: Fitbit sells a whole range of activity trackers (Blaze, Surge, Charge 2, Charge, Alta, Flex 2, One, Zip), some with features beyond counting steps, such as guided breathing sessions, GPS location tracking and heart rate sensing, to suit different users' preferences. Each model is available in its own range of colours and some models include 'special editions' and 'designer collections'. Taglines on the website include 'Only Fitbit gives you the freedom to get fit your way'<sup>21</sup> and 'Fitbit motivates you to reach your health and fitness goals by tracking your activity, exercise, sleep, weight and more',<sup>22</sup> emphasising personal expression alongside fitness and motivation. Individual choice and self-engagement also characterise Google's 'Play Store' and Apple's 'App Store', where users can choose from thousands of apps to help them exercise, maintain a healthful diet or lose weight. Once users install and begin to use such apps, individual choice and engagement remain important. In Fitbit, for example, users are first asked to enter personal information, such as weight and age. The next step is to set personal goals, such as amount of weight to lose, daily amount of exercise. Though the app provides defaults based on recommendations from organisations such as the American Medical Association, the user is still free to set personal goals. This is the user taking 'personal responsibility for detecting and directing [her] own future health'.<sup>23</sup>

Health and fitness apps exemplify Me Medicine in all of the approaches Dickenson identifies: they promise to counter individual health risks, they encourage self-expression, they generate profits for private companies and they focus on individual choice.

### 11.3 Disciplinary Regimes and Health Apps

Yet, how personalised are health and fitness apps? Certainly, each user views statistics specific to their tracked activity. Users might even get feedback or 'coaching' on their activity in light of their personal goals. However, the overall approach is the same for all users: be active and eat and sleep well to meet goals. It is a 'personal choice' to do as everyone should do. In other words, a 'personal choice' but within a framework (of goal-setting) constructed by the apps' designers.

<sup>21</sup> Fitbit, *Why Fitbit*, [www.fitbit.com/nl/whyfitbit](http://www.fitbit.com/nl/whyfitbit) (accessed 2 February 2018).

<sup>22</sup> Fitbit, *Official Site for Activity Trackers & More*, [www.fitbit.com/home](http://www.fitbit.com/home) (accessed 2 February 2018).

<sup>23</sup> Dickenson, *Me Medicine vs We Medicine*, p. 39.

Could it be that these Me Technologies are based on a collective societal and/or economic interest that everyone should act as a responsible citizen? This brings us to the second interpretation of self-tracking technologies: as disciplinary instruments that seduce or force individuals to take responsibility for their own health and fitness.

In *Discipline and Punish*, French philosopher Michel Foucault explains how, from the end of the eighteenth century, individuals became submitted to disciplinary tactics that governed and controlled their movements and behaviours. These disciplinary methods originated in the army, where discipline and dressage had been introduced in the seventeenth century. The success which discipline brought armies engendered a military dream of society: what worked in the army would also work in society.<sup>24</sup> Means of correct training, such as hierarchical observation of individuals, normalising judgements (small penalties, humiliations, corrections, gratifications and ranking) and examinations (combining observation and normalising judgements), were used to transform pupils at school, patients in hospitals, prisoners in prison and labourers in factories into docile bodies.

Activity trackers and health apps match the disciplinary means of correct training, i.e. hierarchical observation, normalising judgement and examination, as described in Foucault's *Discipline and Punish*.

*Observation* – this is described by Foucault as an 'absolutely indiscreet' surveillance that is 'everywhere and always alert' while simultaneously being absolutely 'discreet', since it functions largely in silence.<sup>25</sup> Tracking activity necessarily involves observation of some kind. Activity trackers can count the wearer's steps (by detecting motion) and, in some cases, measure the wearer's heart rate. The same motion detection can be used to track sleep. Though it is uncertain whether activity trackers actually improve health outcomes,<sup>26</sup> the idea behind the activity they encourage is to get people to be healthier by being more active, which the apps stimulate by giving people 'insights on [their] performance'<sup>27</sup> and reminding them to be active, as discussed above. When reminding users to be active, these apps implicitly inform users that the user's activity is being observed (by the app). When insights on performance

<sup>24</sup> Foucault, *Discipline and Punish*, p. 169. <sup>25</sup> Ibid., p. 177.

<sup>26</sup> E.g. J. M. Jakicic, K. K. Davis, R. J. Rogers, W. C. King, M. D. Marcus, D. Helsel et al., 'Effect of wearable technology combined with a lifestyle intervention on long-term weight loss: the IDEA randomized clinical trial' (2016) 316 *JAMA* 1161.

<sup>27</sup> Fitbit, *Fitbit App*, [www.fitbit.com/nl/app](http://www.fitbit.com/nl/app) (accessed 2 February 2018).



are presented to users, however, it is the user observing themselves. This gives rise to a situation in which data are recorded by an individual about that individual – what Katie Shilton calls ‘participatory personal data’.<sup>28</sup> In activity tracking, then, data collection is used both as a means of discipline and self-discipline.

*Normative judgement* (or normalisation) is described by Foucault as ‘a small penal mechanism’ that defines and represses behaviours outside the scope of the law, enforces artificial orders, functions as a corrective, prefers rewards above punishment and ranks individuals according to their good or bad behaviour.<sup>29</sup> It refers to the means of achieving discipline through imposing norms. Normalisation is pervasive in activity trackers and their accompanying apps, but is subtle.

A frequently encountered feature of activity tracking apps is a visualisation of activity levels for a certain period (e.g. the last seven days). Such a visualisation often includes a representation of the desired or recommended level of activity. For example, the Fitbit app includes a screen with a histogram of the last seven days of activity, expressed in steps walked. The histogram includes a line at the daily step goal (set by the user or by default). Such a visualisation directly expresses a norm or standard to which the user’s activity is compared. Though the user is free to set the daily step goal, there is no option to disable the line that represents it.

Also, the app describes the default goal (10,000 steps) as being based on CDC recommendations, reinforcing the idea that this is a norm or standard to meet. If the user zooms in on a specific day, another histogram is displayed (in two-hour intervals). In this visualisation, bars are coloured according to the level of intensity of the user’s activity – red for ‘light activity’, yellow for ‘moderate activity’ and green for ‘intense activity’. Categorising activity in such a way is also a form of normalising. In this case, the user is not free to set the thresholds of each category. Users are also rewarded for certain achievements, for example, by being awarded a ‘badge’ for walking 30,000 steps in one day. Such rewards implicitly label certain behaviour as desirable or praiseworthy – in other words, certain behaviour is normalised in these apps.

Health apps also embed normalisation through defaults for various goals. For example, Jawbone’s UP app allows users to set goals for hours

<sup>28</sup> Katie Shilton, ‘Participatory personal data: An emerging research challenge for the information sciences’ (2012) 63 *Journal of the American Society for Information Science and Technology* 1905–15.

<sup>29</sup> Foucault, *Discipline and Punish*, pp. 177–84.

of sleep, daily steps and weight. The slider with which the user can set hours of sleep also indicates ‘average’ sleep and ‘recommended’ sleep, which is the default. Below the slider it says ‘[t]he National Institutes of Health recommends between 7–8 hours of sleep per night’. The slider to set a daily step goal similarly has indicators for the average and recommended amounts and a text stating ‘[a]verages based on UP users. Experts recommend 10000 steps a day for an active, healthy lifestyle.’ Finally, the weight slider indicates a ‘Healthy Range’ and the user’s current weight. If the user sets a goal below his or her current weight, the text below the slider states

Lose. Eat 500 calories fewer than you burn in order reach your weight goal. There are also other factors that affect weight loss, like sleep, which you can log in UP. If you stick to that plan, you are likely to reach your [xx] kgs goal in about [x] weeks. Men your height should weigh between [xx] kgs and [xx] kgs according to WHO’s BMI formula (Jawbone’s UP app).

These defaults, averages and recommendations impose norms on users’ goal setting. Even if users choose not to follow apps’ recommendations in setting their goals, they still act relative to a norm. As such, their choice of goal is either ‘normal’ or ‘abnormal’. Moreover, once they have set a goal, their activity is judged in relation to that goal and is thus normalised. Even the act of goal-setting is a norm in such apps; activity tracking apps are normalising from the outset.

The final technique of disciplinary control that activity trackers and their apps implement is the *examination*, in which the techniques of hierarchical observation and of normalising judgement are combined. Foucault describes this examination as both a ritual and a ‘scientific’ way of fixing individual differences, in which each individual is pinned down in his own particularity. The examination is at the centre of the disciplinary power:

It is the examination which, by combining hierarchical surveillance and normalizing judgment, assures the great disciplinary functions of distribution and classification, maximum extraction of forces and time, continues genetic accumulation, optimum combination of aptitudes and, thereby, the fabrication of seller, organic, genetic and combinatorial individuality.<sup>30</sup>

In health and fitness apps, the examination is embedded through the ways in which the apps process users’ self-tracked data (observation) in

<sup>30</sup> Ibid., p. 192.



light of the norms the apps include (normalising judgement) to classify the user and their activity. In Fitbit, users' activity is classified as 'intense', 'moderate' or 'light'. Jawbone UP users' sleep is categorised as 'awake', 'light' or 'sound'. Those users' meals get a score and are classified as 'healthy', 'OK' or 'avoid' (if they log food intake). In some cases, apps even actively advise users to change their behaviour. For example, Jawbone UP's 'Smart Coach' feature will tell a user who has slept 3 hours and 58 minutes:

Last night you only slept for 3 h 58 m. Try for more tonight. Skip that new episode of *Dancing with the Stars* or *The Big Bang Theory*. Your body will thank you tomorrow (Jawbone's UP app).

Users are also compared to other users. In the case of Fitbit, the user's activity level is compared to other 'befriended' users and ranked accordingly. Cyclists who use the Strava app can see how they rank in comparison to other users (or 'athletes') on the time it took them to complete a segment of road. Some apps, such as Fitbit, also give users badges for certain achievements, such as new badges for each additional 10,000 steps taken in a day. This comparison to other users, ranking and rewarding achievements exemplifies the examination aspect in health and fitness apps.

What this disciplinary perspective on health and fitness apps discloses is that Me and We Medicine are intertwined: collective norms are taken as default criteria to set personal goals. Disciplinary regimes, especially in the field of health and illness, are always aimed at both the individual and the population at large. In *The Will to Knowledge* (1976), Foucault shows that while health became an ever more important economic value in Western societies, knowledge regimes and disciplinary powers became increasingly oriented toward the optimisation of the health of both the individual and the population. He uses the word 'biopower' to explain the disciplinary forces and policies that incite individuals and society at large to behave as healthily as possible: 'Western man was gradually learning what it meant to be a living species in a living world, to have a body, conditions of existence, probabilities of life, an individual and collective welfare, forces that could be modified and a space in which they could be distributed in an optimal manner'.<sup>31</sup>

Biopower, as a 'political technology of life', evolved over two axes: the one focused on an 'anatomy-politics' of the human body and the other on

<sup>31</sup> Michel Foucault, *The Will to Knowledge*, p. 142.

a 'biopolitics' of the population.<sup>32</sup> In these regimes, the human body became surveyed and disciplined unto the smallest, microphysical level. Today, these disciplinary forces work at an even smaller scale, as the sociologist Nikolas Rose argues in *The Politics of Life Itself*: at the molecular (genetic and neurochemical) level of the human body. The species body, on the other hand, became regulated and controlled in order 'to protect the security of the whole from internal dangers'.<sup>33</sup>

Yet, these disciplinary regimes cannot be understood as either a Me or We type of Medicine. The distinction between strategies governing the individual body and those regulating the species body already became blurred in the nineteenth century, as state authorities and later 'sub-State institutions such as medical institutions, welfare funds, insurance and so on' sought to act upon the population through action upon the human body.<sup>34</sup> The best example to explain this is the political issue of sex, which was at the pivot of the two axes:

On the one hand it was tied to the disciplines of the body: the harnessing, intensification and distribution of forces, the adjustment and economy of energies. On the other hand, it was applied to the regulation of populations, through all the far-reaching effects of its activity. It fitted in both categories at once, giving rise to infinitesimal surveillances, permanent controls, extremely meticulous orderings of space, indeterminate medical or psychological examinations, to an entire micro-power concerned with the body. But it gave rise as well to comprehensive measures, statistical assessments and interventions aimed at the entire social body or at groups taken as a whole.<sup>35</sup>

Continuing this line of thought, Rose analyses how contemporary citizens have become vehicles of biopolitics themselves. Rather than feeling subjected to this politics of life, individuals consider themselves to be free and autonomous beings who deliberately take responsibility for their individual health and well-being. Rose links Foucault's later work on 'care of the self' to the existing disciplinary health regimes. While Foucault considered 'care of the self' to be a technique to criticise existing knowledge and power regimes and to open up new ways to work on and shape one's self, Rose shows that this strategy also further submits individuals to disciplinary power regimes. Contemporary 'biological citizens' not only enthusiastically engage with their own health, they

<sup>32</sup> Ibid., p. 139. <sup>33</sup> Foucault, 'Society must be defended', p. 249.

<sup>34</sup> Foucault, *The Will to Knowledge*, p. 141. Foucault, 'Society must be defended', p. 250. Rose, *The Politics of Life Itself*, p. 53.

<sup>35</sup> Foucault, *The Will to Knowledge*, pp. 145–6.



even claim to have a right to health and well-being and thus to genetic testing, anti-depressive drugs or enhancing technologies.<sup>36</sup> They are convinced that they have freely chosen to behave as healthily as possible.<sup>37</sup>

Deborah Lupton's sociological critique of self-tracking and 'the quantified self' subscribes to this type of analysis. Lupton argues that 'Foucault's writings on the practices and technologies of the self in neoliberalism are pertinent to understanding the quantified self as a particular mode of governing the self'.<sup>38</sup> On this view, citizens voluntarily engage in practices that serve their own interests and conform to those of the state – the responsible citizen self-manages her health through 'self-knowledge' gained through self-tracking ('voluntary self-surveillance').

#### 11.4 We Medicine and Health Apps

Is it possible to develop health and fitness apps that do not conform to Me Medicine? Could health and fitness apps prioritise We Medicine over Me Medicine? What would such apps look like? Dickenson's main goal in *Me Medicine vs We Medicine* is to reclaim medical and biotechnologies for the common good.<sup>39</sup> Rather than focusing on the narcissism, corporate interests and autonomous choice of Me Medicine, she stresses the importance of public health, notions of common interests and common ownership and concepts of mutuality and interrelationships – in short, We Medicine – while dealing with diseases and other conditions that affect our health and fitness.

Historically, it was not Me Medicine but We Medicine—programs like public vaccination, clean water and screening for tuberculosis—that brought us reduced infant mortality, comparative freedom from contagious disease, and an enhanced lifespan. Yet today, many of these public programs seem to be increasingly distrusted, even detested.<sup>40</sup>

<sup>36</sup> Nikolas Rose and Carlos Novas use the term 'biological citizenship' descriptively, 'to encompass all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races and as a species'. See Nikolas Rose and Carlos Novas, 'Biological citizenship' (2002), at p. 3, available at: <http://thesp.leeds.ac.uk/files/2014/04/RoseandNovasBiologicalCitizenship2002.pdf> (accessed 2 February 2018).

<sup>37</sup> Rose, *The Politics of Life Itself*, pp. 146–7 and 154. See also Nikolas Rose, *Inventing Our Selves: Psychology, Power and Personhood* (Cambridge: Cambridge University Press, 1996).

<sup>38</sup> Lupton, 'The digitally engaged patient', p. 28.

<sup>39</sup> Dickenson, *Me Medicine vs We Medicine*, p. viii. <sup>40</sup> Ibid., p. 5.

The question, then, is how we, in primary prevention, can make use of health and fitness apps (or similar technologies) to embody We Medicine rather than Me Medicine. Before we can offer proposals for design directions such apps could take, we need to be more specific about what We Medicine means.

Public health programmes such as those mentioned above exemplify what Dickenson calls We Medicine. It encompasses solidarity and altruism ('We factors'<sup>41</sup>) and involves communal action directed towards communal purposes, common possessions or the common good ('working together for what we have in common'). So, in promoting the idea of We Medicine, Dickenson is calling for a return to, or a reclaiming of, the commons – and creating a 'new spirit of togetherness'.<sup>42</sup>

However, Dickenson identifies two threats to the commons that we see in Me Medicine today and that need to be overcome in order to realise We Medicine. First, there is the threat of free riding: that is, individuals endangering the commons (or communal resource) by 'taking more than their fair share'.<sup>43</sup> One example of this is parents who decide to withdraw their children from vaccination programmes. Sufficient individual participation in such programmes creates a communal health resource or commons – population immunity. Individuals who withdraw their children distrust public health and their view is that they alone are responsible for protecting the individual health of their children – a view fed by market populism, according to Dickenson. By not participating in vaccination programmes, these individuals reap the benefits of population immunity (they are protected by it), but they do not contribute to it themselves. Of course, as Dickenson notes, if too many parents were to withdraw their children from vaccination programmes, population immunity would decline and there would be no commons.

The other threat to the commons is the threat of the commons being enclosed to create a wholly or partially private good.<sup>44</sup> Under this threat, commoners who contributed to the commons are now kept from accessing the benefits of that communal resource. Dickenson illustrates this second threat with the example of corporations such as 23andMe owning and deriving (commercial) value from the commons of the human genome. In this case, individuals' access to the benefits of, for example, diagnostic testing based on these commons can be limited by the private owner of those commons.<sup>45</sup>

<sup>41</sup> Ibid., p. 207. <sup>42</sup> Ibid., p. 227. <sup>43</sup> Ibid., p. 218. <sup>44</sup> Ibid., p. 218. <sup>45</sup> Ibid., p. 222.



So, the commons that We Medicine should reclaim, according to Dickenson, can include common goods, such as population immunity, to which individuals contribute through individual actions, such as undergoing vaccination. It can also be information that individuals contribute, such as genome sequencing information, from which all can benefit through, for example, diagnostic testing based on the communal resource.

Above, we discussed how health and fitness apps and activity trackers exemplify many of the reasons for Me Medicine. Do these apps and activity trackers similarly exemplify threats to a commons? If so, what commons do they threaten? The threat of free-riders, exemplified by the vaccine case, does not seem to have an obvious parallel in health and fitness apps – there does not seem to be an equivalent of population immunity (or of free-riding individuals) in health and fitness apps.

A more plausible parallel seems to exist between individual users tracking their activity through a centralised service such as Fitbit and individuals contributing to 23andMe's genotype-phenotype database. The latter was 'created by the labour, cash and bodily materials of thousands of individuals',<sup>46</sup> but belongs to a private firm. Similarly, users of activity trackers spend money on the means to track their activity and labour (exercise) to produce the data on a private firm's servers. Where the genotype-phenotype database captures a communal resource – the genome is something all humans have in common – from which individuals could benefit, the databases in which the daily activity data of millions of individuals are stored captures a communal resource of knowledge about human behaviour. People have activity (or absence thereof), food intake and sleep in common, and while private firms such as Fitbit do not own the activities themselves, they do own the data derived from these activities. So, as in the 23andMe example, private firms are in a position to limit or deny access to a form of communal resource, to sell the data generated by patients to pharmaceutical companies, private firms in health and fitness apps are in a position to decide in what ways they use or exploit these data. In the case of 23andMe, beside marketing their database, they can use their databases to patent gene sequences and to stake patent claims. In 2012, 23andMe was granted a US genetic patent related to Parkinson's disease without making clear to consumers that it was seeking such patents, ultimately undermining

<sup>46</sup> Ibid., p. 222.

consumers' trust in 23andMe.<sup>47</sup> Though it is not immediately clear how Fitbit's databases could be used to seek patents, similar issues could arise if Fitbit attempts to create intellectual property from aggregated data and profit from it.

Dickenson discusses a number of possible responses to these threats, in the form of various collective movements. One of these responses is the charitable trust model. In this model, contributors to a biobank do not gain ownership rights of (samples and related data in) the biobank, but there is a requirement that the trustees act in the interest of the beneficiaries – so it would not be possible to profit from the biobank. Another response is for an (indigenous) group to claim the right to determine what is done with its genetic data, often by appealing to traditional communal belief systems.<sup>48</sup>

Promoting the idea of We Medicine in relation to health and fitness apps would mean to start with the question of what health and fitness norms we share and what primary prevention means best fit these norms. In the case of air pollution, for example, rather than digitally alerting citizens and helping them to adapt their behaviour to the amount of pollution (thus intermingling Me and We medicine), designers could start by asking what the best primary prevention measures are to prevent health-endangering forms of air pollution. Citizens could be motivated to work together to improve the quality of the common air. Something similar can be seen in Strava's Metro product.<sup>49</sup> Strava is a service that lets people track their cycling and running activity. Strava Metro anonymises and aggregates this data and licenses it to departments of transportation and related organisations to improve infrastructure for cyclists and pedestrians. Though Strava is using data its users have contributed to create intellectual property, the data is ultimately used to improve people's safety.

Prioritising We Medicine in the design of health and fitness apps could start from new sorts of communal identification or new kinds of communal concerns for prevention of diseases. Initiatives such as Science Commons and FOSTER Open Science, which aim to make research data reusable, better accessible and better integrated, are examples of how

<sup>47</sup> Sigrid Sterckx, Julian Cockbain, Heidi Howard et al., "'Trust is not something you can reclaim easily': patenting in the field of direct-to-consumer genetic testing' (2013) 15 *Genetics in Medicine* 382–7.

<sup>48</sup> See also Donna Dickenson, *Property in the Body: Feminist Perspectives* (Cambridge: Cambridge University Press, 2007), chapter 8.

<sup>49</sup> Strava, *Strava Metro*, <https://metro.strava.com> (accessed 2 February 2018).



communal concerns can be taken as the starting point for digital communitarian associations focused on common goods. Dickenson refers to Richard Titmuss's notion of 'the gift relationship', funding the UK blood donation system, to stress the importance of the sense of identification with a wider collective.<sup>50</sup>

We Medicine in the health and fitness apps area also implies investigating the options for common possessions. On the one hand, non-profit public databases could be built that store and analyse the data of tracking activities. Comparable to the charitable trust model, the interests of the contributors would be represented by the trustees. As far as profits are made, they could be used to further research or other common interests.<sup>51</sup> On the other hand, small group databases could be built, in which members share their activity data and have the right to determine what is done with these.

### 11.5 Conclusion

Taking Donna Dickenson's contrast between Me and We Medicine as a starting point, the development of health and fitness apps can be seen as both a type of Me Medicine and a disciplinary regime imposing collective norms on the individual.

The most robust explanation for the rise of Me Medicine in this case is, similarly to other fields of medicine, the dominance of corporate interests and a neoliberal public policy. The responsibility for living a healthy and long life is put on the individual and no longer seen as a communal interest.

Yet, it is impossible to draw a strict boundary between Me and We Medicine. Health and fitness apps are also disciplinary technologies in which public, state and sub-state norms or corporate interests are translated into actions on the individual body. However, Me Medicine claims to be superior to We Medicine when primary prevention is at stake. 'Me often markets itself as clinically superior to We', as Dickenson argues – even though the evidence base for this superiority is weak.<sup>52</sup>

Dickenson's plea to resurrect the commons, in this case in digital technologies that support primary prevention goals, invites us to take

<sup>50</sup> Dickenson, *Me Medicine vs We Medicine*, pp. 214–5.

<sup>51</sup> Dickenson presents the non-profit UK Biobank and PXE International Foundation as examples of a middle way between pure altruism and pure capitalism (*Me Medicine vs We Medicine*, p. 211).

<sup>52</sup> *Ibid.*, p. 57.

a completely different angle. Developing health and fitness apps from a We Medicine perspective, governed by common rather than corporate interests, would imply that users (contributors) would have an insight into and a say in the norms inscribed in the apps; that they are stimulated to identify with communal values and communal concerns; that they know what data are stored and what algorithms are used to analyse these data; and that they have a right to determine what is done with the collected data.

Designers who are willing to bring in more 'We'-ness in the design of health and fitness apps should be aware that Me Medicine in primary prevention often eclipses We Medicine. So, rather than focusing on promises for a better individual life, on narcissism, corporate interests and self-engagement, designers would have to take communal values and common goods as their starting point for design. Design for We Medicine would involve designing for communities rather than individual users. Active involvement and deliberation of citizens and other users in the design of digital primary preventive medicine technologies could be a way to broaden the normative scope of the good life as aimed for in health and fitness apps. Moreover, designers should be aware that group closures (only sharing data with 'people like us') can further encourage the rise of Me Medicine.

In order to bring more We Medicine into health and fitness apps, designers should also recognise that observation, normalising judgement and examination are part and parcel of data tracking technologies. Each design embodies, often invisibly, norms, values and ideologies.<sup>53</sup> Rather than keeping these invisible or implicit, it would be better to submit the embedded norms, values and ideologies to public scrutiny and discussion.

Finally, designers could respect the 'commons' by building databases in which contributors can share their data and stories without giving up the right to decide about these data, in a form similar to the examples of charitable trust fund models that Dickenson discusses.

<sup>53</sup> Bruno Latour, 'Where are the missing masses? The sociology of a few mundane artifacts' (1992) [www.bruno-latour.fr/sites/default/files/50-MISSING-MASSES-GB.pdf](http://www.bruno-latour.fr/sites/default/files/50-MISSING-MASSES-GB.pdf); Mary Flanagan, Daniel C. Howe and Helen Nissenbaum, 'Embodying values in technology: Theory and practice' in Jeroen van den Hoven and John Weckert (eds.), *Information Technology and Moral Philosophy* (Cambridge: Cambridge University Press, 2008), pp. 322–53; Peter-Paul Verbeek, *Moralizing Technology* (Chicago, IL: University of Chicago Press, 2011).



Although there is still a long way to go to resurrect the commons in medicine and to reclaim the various kinds of medical and biotechnologies for the common good, Dickenson's invitation to look for new ways to create a spirit of togetherness in biomedicine undeniably opens up new perspectives to design, develop and use health and fitness apps with more solidarity and in more altruistic We-oriented ways. Just as user-friendliness became a central aim in the design of digital technology, We-ness could become the focus of health and fitness apps.

## The Molecularised Me

### Psychoanalysing Personalised Medicine and Self-Tracking

HUB ZWART

#### 12.1 Introduction

During the 1990s, new forms of technoscience pervaded postmodern society, exemplified by the Human Genome Project (HGP) in the life sciences and by the Internet in the realm of Information and Communications Technology (ICT). These developments initially focused on the construction of a novel 'We', represented by the transpersonal Human Reference Genome (HRG) in the life sciences and by the World Wide Web (as a decidedly transpersonal enterprise) in ICT. Currently, however, against the backdrop of Next Generation Sequencing (NGS) and the emergence of wearable electronic devices, we witness the advent of yet another revolution, again combining genomics with ICT, which claims to entail a shift of focus from *We* to *Me*. Francis Collins<sup>1</sup> and others herald the advent of a new era of personalised medicine, referred to by Donna Dickenson<sup>2</sup> as *Me Medicine*: a development which allegedly transforms human individuals into bio-citizens, empowering them to become proactive managers of their own wellness and health. These bio-citizens become increasingly involved in new practices of the Self, often referred to as self-monitoring, self-tracking, do-it-yourself (DIY) diagnostics, personal informatics or lifelogging.<sup>3</sup> Such practices assist users in maintaining wellness by closely monitoring personal activities such as exercise, sexuality and diet. Indeed, even the molecular effects

<sup>1</sup> F. Collins, *The Language of Life: DNA and the Revolution in Personalised Medicine* (New York: Harper, 2010).

<sup>2</sup> D. Dickenson, *Me Medicine vs We Medicine: Reclaiming Biotechnology for the Common Good* (New York: Columbia University Press, 2013).

<sup>3</sup> D. Lupton, *The Quantified Self: A Sociology of Self-Tracking* (Cambridge: Polity Press, 2016).