# Wearable sensors in new-emerging markets of care (draft title) <sup>1</sup>

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Abstract: EU policy programmes promoting eHealth and mHealth, promise flexible and more personalized care and greater citizen responsibility in managing disease and staying healthy. It is not clear however, how the ICT-based and mobile technologies will affect public health targets and healthcare in the long term. Following Lupton (2013) on enhancement and healthist discourses, our interest in this development concerns the spread of wearable sensors aimed at fitness and health-as-leisure. We examine a set of devices and associated services, including the use of social media to share data and care-relevant knowledge. We explore issues of function and control, of intelligibility and the making of informational bodies and person-hood through media ritual against a backdrop of assumptions about health enhancement. We argue that market successes to-date should be viewed in reference to value creation rooted in cultural trends and traits, not the efficacy, improved healthcare or cost savings promised in policy documents. What is left to account for however, are the ambiguities in the development of business models in quasi-medical markets without adequate legal framework, and who thrive on the mass marketing of data acquisition and gadget use which to-date has largely escaped regulation.

**Keywords**: wearable sensors, health consumers, public health, healthcare policy, terms of use, informational bodies, media ritual

<sup>1</sup> Contributions to this paper draw on a 3 year case study of wearable sensors, cutting across a number of disciplines and assessment methods: the sociology of science, technology, medicine and markets, media and culture studies, ethics, legal scholarship and knowledge assessment.

The development of Information and Communication Technologies (ICTs) to revolutionize healthcare are high on the EU's Digital Agenda (EC, 2010; Digital Agenda for Europe). It involves high-performance computing and data services and, more recently, the opportunities associated with the use of sensors for mobile healthcare (*mHealth*). The idea is that medical, physiological, lifestyle, activity and environmental data can form the basis for evidence-driven care and marketing (EC, 2014). Research and development of sensors is already focused on miniaturization and wearability, self-sufficient energy production and computer processing that pushes the boundaries of what is technically possible (e.g., the Guardian Angels).<sup>2</sup> As the 2014 EC Green Paper on mHealth puts it, sensor data is expected to grow in the next decade from 10% to 90% of all stored data. Similarly, an influx of real-time data is anticipated, among other things, for use in individually targeted drug therapies (also EC, 2012).

This area of innovation is indicative of the pivotal role given to ICTs in solving the challenges of sustainable healthcare and an ageing demographic (Mort, Roberts & Milligan, 2011). One can argue that the 2004 eHealth Action Plan set the tone by encouraging EU-wide deployment of electronic records and mobile monitoring services (Commission, 2004) and, until recently, the largest market predicted in the emerging mobile care sector is associated with changes in clinical and hospital practices, extending care to home monitoring, e.g., in rehabilitation, telecare and assisted living.

Promoting the eHealth Action Plan and its continuation (2010-2020) centres on arguments of cost reduction and efficacy in services to publics. eHealth and mHealth initiatives find resonance in public health programmes exploring the potential of self care for healthier lives, disease prevention and less dependence on medical professionals and facilities. The green paper on mHealth mentions novel ways to promote healthy behaviours and responsibility, "through sensors that detect and report vital signs, and mobile apps that encourage them to adhere to diet and medication" (2014, p.5).<sup>3</sup> A recent report by the European Science Foundation also recommends that healthcare professionals work with ICT experts to define, for example, how smartphone-enabled applications can help as decision-supports,<sup>4</sup> in effect promoting the new technologies as supports to conventional healthcare. It recommends a flexible health technology assessment (HTA) framework to ease the adoption for *added value* (ESF, 2012). The drawback is that, with few exceptions, practitioners still need to see further evidence of feasibility of eHealth and mHealth solutions, of clinical and economic benefit (e.g. EC, 2011, 2014).

The early discourse on eHealth centred on the growing pressure on healthcare provisions in

<sup>2</sup> See for example the strategic research agenda of the industry-academe consortium, *Guardian Angels* (GA), one of four finalists in 2013, in the Commission's Future and Emerging Technologies (FET) Flagship Initiative. <u>http://www.ga-project.eu/</u>.

<sup>3</sup> See also the UK Self Care Forum <a href="http://www.selfcareforum.org/">http://www.selfcareforum.org/</a> and the Expert Self Care initiative <a href="http://www.expertselfcare.com/">http://www.selfcareforum.org/</a> and the Expert Self Care initiative <a href="http://www.expertselfcare.com/">http://www.expertselfcare.com/</a>.

<sup>4</sup> Recommendations 7.3, p. 50

caring for older populations. However, the most recent trends are in fitness and wellbeing gadgets to support healthier lives, aimed at lead markets of affluent consumers and profitable business. The devices we commonly see on the shelves of pharmacies and outlets offering consumer electronics and outdoor gear, have their origin in hospitals and clinical care, in professional sports, military and rescue applications. They are designed to keep track of body functions and environments, and they are location, tracking and navigation devices relying on GPS units and geo-information.<sup>5</sup> The smartphone is also used as a 'hub' for data gathering, processing and communication, relying on smartphone-enabled capabilities and apps to capture and manage information.

Good quality sensors are not cheap which may explain, in part at least, why the typical buyer is willing to spend approximately £90 on the average for a healthcare and/or fitness sensor that can be paired with smartphones (IMS Research, 2012, cf. Sarasohn-Kahn, 2013). Consumer electronics are taking on medically-relevant purposes here and we observe a blurring of boundaries between professional care and the self-administration of care. But, if the new gadgets are not strictly classified as medical, and regulated as such, they sit in a policy vacuum. In this new field of what we might think of as promissory health enhancement (Lupton, 2013), there is no clear legal framework, with binding rules, to ensure that developments, uptake and use are safe, as the green paper on mHealth puts it (3.3, pp.10-11).

In this paper we consider this new-emerging *quasi-medical* marketplace, as it appears in relation to our own experimentation and experience of using a set of smartphone-compliant performance and tracking apps. These products have established themselves in a market of *fitness-as-leisure*, a market of self care, prevention and enhancement which is ambivalent in terms of establishing medical and care-relevant value. We observe tensions between, on the one hand, medical regulation and healthcare policy and, on the other hand, new patient-consumers and their identities and know-how. We discuss a set of issues associated with the adoption of these devices in unstructured and semi-structured environments. Drawing on insights from our respective disciplines and assessment methods,<sup>6</sup> we address the promise they hold, of how they should function and of the control they afford the user. We explore their intelligibility in terms of what users can learn and what knowledge users produce and share. Finally, we look at the trends in data acquisition associated with these gadgets where we observe a growing ecosystem of platforms and interoperable aggregators competing for people's behaviour and tracking data.

### New-emerging technologies in new-emerging markets

A 2011 public consultation on eHealth shows that the incentives of those who fund or reimburse care remain unclear (EC, 2011). Neither financial/economic nor quality incentives are shown to be very strong. Self-funding and increased availability of ICTs need not translate into

<sup>5</sup> See Lupton 2013 for detailed overview of devices and apps flooding the market.

<sup>6</sup> See footnote 1.

large-scale commercial opportunities either. The report relays serious doubts that the benefit assumptions (efficacy, better services and reduced costs) will ever come to pass while, paradoxically, most participants in the consultation still support those selfsame assumptions. This follows a pattern exemplifying belief in technological progress, too ingrained and path dependent to be substantively challenged. At the same time, pilots in eHealth and mHealth raise deeper issues about costs and benefits within larger systems of social care, housing and healthcare.<sup>7</sup> ICT-enabled interventions introduce organizational and institutional complications which then are time-consuming and costly to correct (e.g. Schillmeier & Domènech, 2010). The question of what constitutes failure or success, and disagreement on how to gauge results, contributes to the complexity in this area (Magnet, 2011). Different players are seeking clarity on their roles and responsibilities in the new value chain and self-funding schemes and self-planning of one's future health-monitoring and care needs are emerging in the commercial marketplace.

The trend toward the self-management of health relates to visions of personalization as *consumerization* and *responsibilization*<sup>8</sup> against a backdrop of growing concerns over public spending (Schmillmeier, 2010). In 2010 "people with long-term conditions (LTC) accounted for more than 50% of all GP appointments, 65% of all outpatient appointments and over 70% of all inpatient bed days in England" (UK HL, 2013). Further estimations are that LTCs afflict approximately 30% of the population while the treatment and care of people with LTCs accounts for 70% of the total health and social care spend (UK DoH, 2010; also Clarke, 2005 and Harrison & McDonald, 2008, on shifts in the moral responsibilities of citizens). The perception of LTCs is that the majority is ageing and lifestyle related, and all considered to be on the increase. There is evidence that such conditions can be significantly delayed or avoided with adequate self care and early intervention. Accordingly, a dominant policy view is that in order to ensure future access to high quality care, the management of ageing and lifestyle related LTCs has to shift toward prevention and responsible self management. A discourse of healthier citizens as better citizens emerges here, casting some conditions (e.g. obesity and addiction) as blameworthy with implications for adjustments in the delegation of resources.

While the new trends are redrawing the boundaries between state, private enterprise and citizen responsibilities, markets drive the innovations.<sup>9</sup> There is a surge in online-based services, self-help and data sharing for a vast range of common conditions, and injuries. We observe do-it-yourself (DIY) market models of health assessments and consultation. The growth in the sales of test-kits, self-monitoring devices, and other (both lawful and unlawful) products has rapidly increased, with ABI research in 2012, predicting 170 million wearable sensing devices alone on the market by 2017 (cf Ranck, 2012, p.5).

If these predictions are anything to go by, wearable sensors are becoming mainstream and

<sup>7</sup> E.g. the EFORTT project, <u>http://www.lancaster.ac.uk/efortt/</u>

<sup>8</sup> The 2010 report on medical profiling and online medicine by the Nuffield Council on Bioethics, defines four categories of personalization (p.30).

<sup>9</sup> Typically, the USA is seen as the *prime mover* of market-driven innovation, but European markets and citizensas-health-consumers appear to follow suit in this area of development.

recent findings in the sociology of heath and medicine and health informatics can shed some light on who the customers are, what their expectations are, what healthcare they actually receive and what the incentives are for them to sign up for health enhancement programmes (e.g. Lupton, 2013; Mort, Roberts & Callen, 2013). The Quantified Self (QS) movement also provides insights, being dedicated to '*self knowledge through self-tracking*'. These communities incorporate technology into data acquisition on various aspects of daily life, consumption and performance. Moreover, QS operates in a mode of self-conscious investigation of comparative and open data gathering, creating platforms to aggregate data from different commercial and health service platforms (Fotopoulou, 2014; Nafus & Sherman, 2014).

Policy developments are looking to discover self-care incentives aimed at common ageing and life-style related conditions which creates several tensions. More pressure is on individuals to actively pursue healthier lives, for example, to self-monitor for health status indicators as if healthcare was reducible to a set of parameters to monitor. This is also an ambivalent terrain. Test-kits, wearable sensors and other types of electronics play a role in supporting individuals who, for one or another reason, self-monitor. There are standardized and certified products on the market for precisely those purposes. However, many of the new biosensors effectively are consumer electronics in a market of gadget use and service support which is hard to subject to accountability if devices fail in one or more aspects of function and control that is essential to certified care. Their uses are better viewed as part and parcel of contemporary digital and social media culture, which historically has disadvantaged ageing and vulnerable populations.

With that in mind, rather than attempting an analysis that seeks to situate the new technologies on a continuum with developments in healthcare and public health programmes, we argue that an essential aspect is the value-creation made possible by catering to new-media trends and behaviours. More precisely, the consumer electronics we have examined for this paper offer unique insights into data acquisition and gadget use as marketable products in the market sector of self care, health enhancement and leisure.

## Exploring gadgets

We present in this paper our analyses of a set of devices and services on the market. We explore the use of smartphone-enabled apps to track and measure cycling routes and performance. These cheap (or free) apps promise to do the same job as high-end cycling computers, the latter of which are widely used by competitive cyclists. They need to have reliable GPS sensitivity tracking capabilities—tracking distance, elevation, speed, grade and other data of import to cycling. They may also have to withstand rapid change in temperature and humidity, and they need adequate battery life. Regarding the last on this list, *power*, wearable monitors and critical safety technologies may need uninterrupted power which is recognised in visions of future mobile wearables and environments with sensing capabilities hinging on sustainable energy ecology through the capacity to harvest energy—*kinematic energy, body heat* and *bio*-

*inspired energy* production such as synthetic photosynthesis.<sup>10</sup> However, there is little evidence to date that wearables are leading this kind of innovation, with notable exceptions such as the *smart e-bike* project.<sup>11</sup>

Another choice of exploration is Fitbit which has been on the market since 2008 to monitor activities linked to weight loss and fitness. It has a customer base whose actions and communications can be observed online. We examine online blogs, developed as part of Fitbit services, with categories such as *development* (where possible future developments are discussed), *health info* (explaining why the use of Fitbit is good for health), *general* (with a range of general topics relating to Fitbit), and *press and awards* (Fitbit conference presentation, a prized Fitbit product, etc.). We analyse the user interface from exploring first hand the use of the phone app, the device screen and the website. Then, we examine representations in news media and technical reviews, looking specifically at UK print news over one-year period.<sup>12</sup> We found coverage primarily consisting of reproductions of press releases from consumer electronics shows and promotional materials prepared by the company and its distributors. In this coverage, grand visions manifest in seemingly mundane applications, visions of the future of healthcare, and a transformation of consumer electronics. Fitbit serves to anchor innovation imaginaries about a wearable revolution, an electronic health record revolution and that *the future is here*.

These choices of empirical exploration are useful in reference to technology development, market development and technology assessment research. We observe convergence of different sectors: medicine, lifestyle and fitness support, telecommunication, micro-electronics and software. We observe that lifestyle and fitness supports take on functions reminding of healthcare. However, rather than focusing on and assessing continuities in technology design, cutting across different device and service classifications, our empirical data suggests we should look closer at the perimeters of use being drawn around manageable environments and predictable behaviours that are exploitable for mass-marketing. Rather than assessing where the boundaries lie between medicine, healthy living and sport in the midst of a public health discourse on overweight unhealthy citizens, we examine the new behaviour trends in reference to their cultural locus in social media, in narratives, knowledge creation and sharing. The shift in focus from high-end professional grade to smartphone-enabled and mainstream also appeals to our study interests, i.e., to critically explore and push to the limits of what can be expected of hardware and software capabilities as they currently are put to practice.

The gadgets we explore and the behaviour trends associated with them invite complications which bear on issues of function and control, of intelligibility and the making of informational bodies and person-hood. There are privacy and data protection issues to consider with behaviour and use data being the prime commodity. Wearable sensing systems are ideal for data mining

<sup>10</sup> E.g., the Guardian Angels initiative <u>http://www.ga-project.eu</u> .

<sup>11</sup> The *smart e-bike* research project at <u>http://www.smart-ebikes.co.uk/</u> .

<sup>12</sup> The news articles referred to here cover April 2012-2013. We took all UK newspaper references to Fitbit and found a total of 140 articles. Of these only 3 significantly challenged the promotion of Fitbit as a cool new device to help manage and control weight and wellness.

with which both individual and group profiles can be constructed, e.g., on interests and preferences used for targeted advertising. They are ideal to isolate information on risky behaviour, medically-relevant information, physiological features and performance, including health risks, all of which can be inferred from relatively trivial data (Kosinski, Stillwell & Graepel, 2013). As we discuss with examples from our explorations, the advertising sector is particularly well situated to exploit these data as currency with which users effectively 'pay' for the services they sign up for.<sup>13</sup>

#### Domesticating a wearable

Ideally, wearables are always turned on. They are easily worn and can always be accessed. They gather data and permit access to information and communication in real-time (see Ranck, 2012). The very idea of wearability refers to comfort and utility but also to next-to-invisibility or fashion which is evidenced in convergence of fashion, usability and specified practical purposes. As Sarasohn-Kahn argues (2013), merging such qualities has become critical to the success of the new products and services, and a conspicuous example of how this can fail is the reaction to Google Glass, that it makes you look stupid (Yarow, 2014; Souppouris, 2014). In short, there are new form factors to consider as well as usability and cross-over purpose opportunities.

There are many ways in which devices remain unfamiliar and use scenarios uncertain. Devices can fail to properly support an intended use, although, it may seem trivial to appropriate, say, a smart cellular phone given how widespread the uptake is. But, rather than trivializing the appropriation of mobiles and wearables, one should perhaps ask how getting used the workings of a device while negotiating its purpose and use-value, juxtaposes with uncertain, failed and fragmented uses—with complexities and uncertainties in assembling and using gadgets, systems and services which could otherwise be considered successfully designed products.

### Embracing the functions: purposes, infrastructures and interoperability

Cellular phones pose a number of functional challenges. Once a smartphone is up and running, there are good chances of experiencing poor battery life, unreliable phone signals and data services, with these problems being exacerbated considerably when the wearable is operated outside built-up areas. The smartphone's lack of purpose-specificity, as opposed to specialized professional-grade equipment, also makes it ideal to capture and exploit any number or combinations of use data, of behaviour and performance data, while obfuscating issues of control and protection of what is essentially private and potentially sensitive.

For example, the (un)reliability and (in)compatibility of smartphone-enabled cycling apps in use outside built-up areas, begins to foreground the use-purposes for data capture in their design, while the question of comparison or continuity with specialized equipment quickly fades into the

<sup>13</sup> See 2010 BBC TV documentary series *The Virtual Revolution* (2<sup>nd</sup> episode, *The cost of free*).



**Figure 1**: Recording the ride over Splügenpass into Italy. Access to global positioning drops out in parts of the route (yellow) that are actually quite exposed.

background. We quickly learn not to expect continuous recording of tracks over vast distances, or for hours on ends. First, the device would have to rely on standalone GPS capability (S-GPS), i.e., satellite-based positioning, rather than so-called assisted GPS (A-GPS) common in cellular phones, using cell tower access. Some phones have built in a hybrid of the two but the A-GPS function is unreliable away from towns and villages and so is phone-enabled data access. S-GPS units in smartphones are typically also of much poorer standard than in specialized devices (see figure 1).<sup>14</sup> Secondly, the device would have to be operating purpose-specifically with minimum overhead at all times, in order to secure reliable energy for longer than 4-5 hours at the very best. Many specialized gadgets promise 15-18 hours of reliable energy.

By engaging a *trial-and-error* mode of establishing reliable functions and use-purposes, we learn that specialization is not one of them. Some of the apps we tried are promoted as specialized, say, to track and measure outdoor and endurance activities, while that is effectively general purpose in *using and generating tracks* for online data display and sharing (running, cycling, walking). We learn that functions fail when devices are used in un-structured situations and environments. We observe certain degree of interoperability, e.g., to pair bluetooth-compliant sensors with activity recordings, linking data on

heart rate, blood pressure or other body functions. Similarly, articles about Fitbit discuss linking the data with other databases. Some mention interoperability with electronic health records (e.g. Arnold 2012). Fitbit is said to be pre-wired for the electronic health record revolution but is also linked, for example, with the activities of the QS. There is no evidence however, of reliable system interoperabilities between different products on the market. Like many other products, Fitbit works for the general purpose of *monitoring and measuring* a set of pre-given indicators

<sup>14</sup> S-GPS units often work with significant delays in narrow valleys in-between high mountain tops and a similar problem is prevalent in-between buildings which is why A-GPS has gained momentum in cellphone design.

that have been worked out independently by the different companies in terms of *standards*.

The range and format of information Fitbit users can share is effectively prescribed by the platform, i.e., quantified accounts of food consumption, physical activity, weight, sleep, mood and allergies, allowing free-form non-quantifiable content to be shared only in separate *journal* entries. The interface design is scoping for the collection of behaviour and performance data for the benefit of users' presumed goals, and the social networking elements of that seem *as if* they would be instrumental in meeting that aim (see Atzori, Carboni & Lera, 2013). Similar choices are evident in the interface design of apps and websites for outdoor and endurance activities, i.e., to scope for collecting performance and route data using prescribed data types and formats.<sup>15</sup>

One conclusion to draw here is to say that it is not yet clear who the customers are. We observe general-purpose hardware and many of the app designs are opening the doors to all manner of potential use-purposes. For example, we observe that apps for outdoor and endurance activities support access to already registered workout routes, most of which lie within the reach of highly populated areas where such activities are a regular feature of everyday life.<sup>16</sup> Thereby, the app designs appeal to communication and comparison with others on those same routes. We also observe how Fitbit appeals to the most common denominator of being more active and eating well for weight loss and overall health improvement. In other words, the new devices and services aim to recruit in numbers and scope for data in numbers, by tapping into and prescribing confined, pre-given and more or less predictable behaviours within more or less contained environments. The outcome is a growing market of particular kinds of gadget use and data acquisition, with a promissory, albeit, ambivalent relationship to public health.

### Being in control: healthism and enhancement

The Fitbit *development* blog announces and advertises new products and applications. The authors are employees who appear to be knowledgeable about losing weight and being healthy:

It's about reaching your goals in the most efficient and fun way possible. And it's about becoming as healthy as you want to be (Iking, 3 October 2011).

However, what 'healthy' could mean for the customers is not explained very well and the claims are not justified, although, on the topic of goal-reaching and fun, our assessment of the media coverage shows that Fitbit is treated as a *cool* gadget. It is variably called *device*, *gizmo*, *wearable* and,most frequently, *app* which then becomes the pun in headlines such as 'appy days' and 'if you're appy and you know it'.

There is an emerging ecology of mobiles evoked through this language and the framing helps

<sup>15</sup> To large extent, the choice of data and data formatting coincides with the corresponding professional sports, e.g. speed, gradient and cadence.

<sup>16</sup> Cycling as amateur sport is widely popular on routes in and between residential surroundings, for commuting and workout, also longer training sessions (3-6hrs) on registered routes further afield. Similar can be said about running.

to locate their use within digital and media cultures. Simultaneously, they are treated as part of bigger visions of telemedicine, big data and electronic records. The following quote is from *Medical Marketing and Media (Devices & Diagnostics report)*:

[o]ne of the advance guard of a new breed of medical device-one that's part app and part gizmo and interfaces with smartphones to allow patients with chronic conditions like diabetes an easy, DIY way of monitoring their health and sharing that data with their doctors. It's a tool tailor-made for this era of Big Data, empowered patients and ever fewer primary care physicians, who have less time (Arnold, 2012).

Integral to this and similar depictions, lies the question of how to use biological knowledge to manage a public health crises. For example, Fitbit generates data through a selection of indicators which, in coming together, suggest a 'slimming aid' according to *The Sun*. '[I]t counts the number of steps you take and converts the data into calories burnt'. This way of characterizing biological data – as generated by quantifying walks, running, biking and swimming activities – together with calorie intake and weight measurements, is the feature most frequently represented. It is *a device that will manage* by measuring.

At this juncture, it is relevant to ask what exactly the expectation is of Fitbit's assistive role in people's lives. There is a form of agency ascribed in that the *device will manage* and that users will communicate with the devices as *companions*.<sup>17</sup> The company is also portrayed as a helping hand:

Fitbit, is dedicated to helping people lead healthier, more active lives. We take a common sense approach to fitness, and believe that the key is to make it easier for consumers to be more active, eat smarter, and get enough sleep — in short, that small changes to your daily routine can add up to big results.

Entries like this one in the *health info* section stress the small changes through specific actions: taking 10.000 steps a day, sleeping 8 hours, drinking enough water, monitoring blood glucose, albeit, none of these actions require the use of Fitbit in the first place. The product is positioned as a personal trainer, an agent and companion, helping people realize a routine of self-improvement and health enhancement. But, while the *health info* blog does not provide much information on healthcare relating directly to the use of Fitbit, one can argue that its use is media ritual which in and of itself has a purpose of cultural value (Couldry 2003). Logging information and checking stats is a mundane, individualized and often tedious activity (see user reviews, e.g., Waltz, 2012). However, the imaginary of a collective and a community evokes these actions (Lupton, 2014), and the media ritual invokes positive affirmations collectively, through which users can reassure themselves that they are proactive, in control and taking responsibility—in short, not just slimming but meeting a healthist vision of empowered and better citizens.

A conclusion to draw here, is to say that Fitbit invites users to explore and create stories about

<sup>17</sup> Sleep companion, activity companion, weight companion, and so on.



Figure 2: A glance at a person's profile on Fitbit

their bodies, and to represent them back to themselves through an online interface on which the tracking data is rendered. The data are linked to forms of biographical storytelling and tools to incorporate self-identity into the data spectacle (Gregg, 2015). The interface consists of the smartphone app, the website and the Fitbit screen or dashboard (figure 2), all of which are similar to other fitness and health app designs such as the ones we have explored for outdoor and endurance activities. In fact the 'dashboard' has become the interface of choice, from Twitter and

blogging interfaces, to wearables with navigational connotations reminiscent of cybernetics connections to steering and self-steering. These devices further embed the design of social networking features (profiles, friends/groups) with visual and textual elements of quantified data, infographics, game features and more. In the next section, we further examine these forms of mediation in reference to the making of narratives, knowledge and sharing.

## Making sense of the mediation

If healthcare and medicine is looking to digital media to push some of the costs and responsibility of care on to people, the question of what is the most relevant biological knowledge to assist in this *self-making* becomes one of the stakes. The re-formulation of citizens as consumers and prospective patients operating in a hopeful economy of biological citizenship is well documented (e.g. Rose & Novas, 2003; Rabinow, 1996). However, the behaviour trends in the making of narratives, knowledge and sharing we observe, have no obvious relationship with their imagined role in enforcing healthier living.

Reasoned care-relevant explanations and justifications are lacking in all the blog entries on why the Fitbit companions should be used in the first place. Users may refer to medical authorities, experts and doctors to support their health imaginaries, however, those references are not always clear on who the experts are, nor their authority in the field. Consider this example:

The American Heart Association uses the 10,000 step metric as a guideline to follow for improving health and decreasing risk of heart disease, the number one killer of men and women in America.

In following up on this recommendation of 10,000 steps per day, we observe that it was established by journalists (on another website referred to by the AHA), suggesting how women could become fitter and healthier. Similarly, other organizations and experts are referred to in the blogs without adequate clarity on how knowledgeable of the subject they really are. Blog entries authored by Fitbit employees are all signed, *Fitbit team*, while different pseudonyms (e.g. bazzarelli, Iking, syuen) differentiate individual authors at the top of each entry. The persons behind these pseudonyms are nowhere revealed even if they are positioned as knowledgeable. They use friendship appeals to attract users, professional 'hats' and pseudo-scientific references to legitimize their claims. All the entries are also written in first person plural, 'we', to establish a connection between the producers and readers of the blogs, implying a collective position whether or not such positioning can be ascertained (Moniere, 2007; Myers, 2010). The authors' intention to include wider audiences is quite clear. The entries are written in a way that either speaks on behalf of readers or directly to them, however, it remains unclear who is actually writing these entries and thereby producing and presenting *knowledge*.

While the knowledge claims we observe are not certifiable in the conventional sense of being professionally and/or academically regulated, we suggest that the media ritual of data logging,

communicating and sharing, facilitates knowledge production of a kind. In and through these activities, the users along with Fitbit staff co-produce imaginaries and knowledge about healthy lifestyles, self care, fitness, and more, which then have claims upon know-how and future activities. Interfacing with a device screen, a smartphone app and a website, the central action is to log information, then reading that information as it is reflected back in infographics and diagrams (figure 2). Quantified accounts are contextualized within an interpretative framework for the process of sense-making and knowledge creation. For example, user measurements are compared to certain targets (e.g. 10,000 steps per day), to real world or fictional objects (e.g. the equivalent of climbing the Empire State building), and to other people's achievements which then cultivates a competitive data-sharing environment. *Badges* and *levels* are the motivational tools to that effect, i.e., game elements of challenge, reward and positive reinforcement. Indeed, *gamification* is integrated here as a marketing strategy (see Zichermann & Cunningham, 2011 on this issue).

Fitbit also uses emotional appeals to encourage attachment to the devices, e.g., '*Flex*<sup>TM</sup> is your perfect companion', whereby companionship is key feature transposed onto the interactions. This artificial 'pet' type relationship resonates with the Japanese virtual pet, Tamagotchi, and other virtual companions and care relations (virtual gardens or homes). This way of constructing devices as companions – despite its long cultural history – poses a challenge to ordinary understandings of companionship, of the appropriate distribution of sentiment and peer-to-peer relations. Companionships form in hybrid world of humans, animals, virtual inanimate and semi-animate objects but Fitbit invites only a superficial companionship with other users in spite of the encouragement to share data and achievements, and discuss issues of health and fitness-related nature. This is particularly evident in the ways in which comparison of achievement is displayed on the screen.<sup>18</sup>

To summarize, we observe considerations in the interaction design, and success in attracting users into a relationship with Fitbit. This mode encourages users to log, contextualize, push targets, narrate a self, and share experiences and learnings. It may therefore seem well founded to say that these successes reflect favourably upon the promise of managing one's health and well being. However, the broader question remains unanswered, how self care of this kind contributes in the long term to public health targets and the administration of healthcare. What strikes us in our observations of interactional features and mediation, is the extent to which behaviour and activity data is scoped for purposes that are not stated upfront, nor likely to be well understood by users. We see similar trends across all the gadgets we explored in our study, a reflection of what might be thought of as *algorithmic culture* or conditions of life in which the collection of data for self-monitoring and self-making rests on data-collection structures and management for governance, power and profit.

<sup>18</sup> One can argue similarly that relating to others' achievements as companionship is either superficial or absent using Strava, MapMyRide, Endomondo and other outdoor and endurance apps.

#### Data acquisition and gadget use

Only a tiny amount of the media coverage is critical of self-tracking as healthcare. It construes data generation as a type of pollution, privacy an area of concern, and emphasizes that measuring by itself does not amount to much health management. Perhaps, the most critical assessment positions fitness tracking as part of the big data industry, captured in the headline, "Your body isn't a temple, it's a data factory emitting digital exhaust" (Mahdawi, 2013). The critical media coverage draws on review articles and press releases from consumer electronics shows, but this more targeted critique also references reports suggesting that the French government would attempt to impose a data tax on companies that profit from *user-generated* data.

The dominant business model in this new market exploits social networking and data sharing with low or no cost to users, for big data processing to research behaviour, health and illness trends. Rights to privacy and data protection often do not apply if profiles are constructed from anonymized data, i.e., the target unit is not a particular person, but a statistically clustered *type of person* or member of a certain *kind of community*. In terms drawn from critical theory this unit is *dividual*, rather than individual, a unit in a framework of governance in which type of data is more significant than type of person.<sup>19</sup> And, it is with this kind of framework in place, that an ecosystem can flourish of platforms and interoperable aggregators competing for access to behaviour and tracking data.

It is important to note that most people are only vaguely aware of profiling classifications that take place, albeit, notable exceptions are among QS members. Processing operations are too opaque, thus also the relationship between front-end data collection and back-end use within larger systems. This is particularly problematic in the face of existing data protection law that requires operational transparency for adequate oversight of data operations and management— also for contestation in a court of law as part of due process (Hildebrandt & van Dijk, 2012). There are at least two approaches to what can be done here. One is the approach of self-trackers – QS, artists and activists – who engage in opening up the data and share platforms to create new use-data relations (Nafus & Sherman 2014). Another approach is to explore the legal ramifications of data collection and what happens to these data, by observing the *sign-up* process and *terms of use* on a case-by-case basis.

For example, the Strava app brings together an online *Strava community* of cyclists who upload their tracking data and compare with one another. MapMyRide suggests either using Facebook for sharing or signing up with their online services (figure 3), and Fitbit strongly encourages sharing, although users can in principle keep their profiles private and make choices on what to share.<sup>20</sup>

<sup>19</sup> See Deleuze & Guattari, 1983, on capitalism and schizophrenia, their concept of *dividuation* and theory of desire. It is also the case with inductive data mining, that new types of persons emerge, correlated on unexpected criteria.

<sup>20</sup> In the case of MapMyRide, it is only after some tinkering that the newcomer realizes that 'sign-in manually' is a *private* option (figure 3).



Figure 3: Joining *Strava* and *MapMyRide* in 2014.

Once information is shared on Fitbit, the *terms of use* specify that the user grants the company the "perpetual, irrevocable" right to "commercially exploit any text, photographs or other data and information" submitted to the services.<sup>21</sup> Users waive their right to so-called *user-generated content*, meaning "content posted on message board posts, blogs, journals, food and recipe submissions and user comments".<sup>22</sup> Similarly, using the MapMyFitness products grants the

<sup>21</sup> These *terms of use* present a strange hybrid of privacy law and something akin to copyright law. By framing data and information as *user-generated content* and defining its use according to terms of copyright licensing, the locus of regulation and control of flows of private information is not in accord with privacy and data protection, but with quasi-intellectual rights. *User-generated content* is not a widely accepted legal term, however, it resembles copyright to the extent that original input is required. But, this is misleading because it could be questioned whether the data and information in question exhibit the "certain amount of creative effort" necessary to qualify as copyright user-generated content (OECD 2007). It is also misleading to suggest that data protection is waived. Rights and obligations concerning personal data cannot be so freely contracted away. For instance, *consent* is always revocable, never perpetual.

<sup>22 &</sup>quot;Subject to Fitbit's adherence to the privacy settings you select within the Fitbit Services, you hereby waive any rights of publicity and privacy with respect to the User Generated Content and any other legal or moral rights that might preclude Fitbit's use of the User Generated Content or require your permission for Fitbit to use the User Generated Content" (https://www.fitbit.com/terms).

company right to exploit user content "for any purpose, commercially, advertising". The terms of use explicitly state that "if you do not elect to mark your User Content as Private or available for a limited group of users ... MapMyFitness cannot and does not guarantee the privacy of such User Content."<sup>23</sup> It is also noteworthy to look at the access users give to other data on the smartphone. The company's privacy policy states that the device will utilize personal identifiable and non-identifiable information, including financial and location-based information, and aggregated information on user demographics, interests and behaviour. The policy specifies that location data are shared with Facebook and Google, and "the collection and tracking of a User's location information may occur even when MapMyFitness apps are not actively open and running".<sup>24</sup> It also specifies the use of aggregated data, how the company engages in data mining and group profiling to improve the services to its members. Personal information will only be shared with other companies with an explicit opt-in consent, but that does not preclude MapMyFitness using the information internally to construct profiles, probe for interests, preferences and orientations, and route back targeted content (see Wauters, Lievens & Valcke, 2014, on the issue of protection).

Setting these findings aside, that are ways in which performance and tracking data *can* be managed privately and communicated online at the discretion of users. Many gadgets on the market do not lock users into social networking commitments. In most cases, users can keep the data they aggregate private, and present contexts and analyses at some preferred networking venue. But this requires computer and data literacy well above the average, and a genuine commitment to data acquisition and management for the purpose of being oneself in charge. As it currently stands, users typically have no control over where their data are stored, how they travel, are processed, and for what purpose (Quinn, Habbig, Mantovani & de Hert, 2013).

## Wearable sensors as mass-marketable products

Arguments that tie wearable sensors to policy programmes on healthcare and public health continue to have currency. Uptake and use is explored and analysed in reference to grander visions of a revolution—of an evolving ecosystem of objects, functions, services and incentives to enhance one's health. One thing we have learned in this respect is how the pairing of sensors with smartphones attracts the development of quasi-medical applications.<sup>25</sup> However, medical devices are subject to strict regulation,<sup>26</sup> and fitness and wellbeing apps typically do not satisfy that criteria, let alone the smartphone itself. There have also been problems with smartphone-enabled medical applications that do not adequately cope with medical data standards, e.g., the

<sup>23</sup> http://www.mapmyride.com/terms\_of\_use/.

<sup>24</sup> http://about.mapmyfitness.com/about/user-privacy-policy/.

<sup>25</sup> In expert consultation in Brussels (5-Nov-13), a policy lobbyist called for the medical grading of smartphones. This is far from straightforward, given their general-purpose design and the cost of incorporating higher quality components, e.g., S-GPS and data-processing units which then will offset smartphone markets.

<sup>26</sup> These conditions are enshrined in EU Council Directive 93/42/EEC concerning medical devices.

Pfitzer's Rheumatology Calculator.<sup>27</sup>

These learnings point to ambiguity, encouraging innovation in eHealth, mHealth and associated technologies through policy programmes. On the one hand, high expectations are invested in promises of greater flexibility and personalization in care, and the new products sit well with political ideals in Europe about innovation and entrepreneurship. On the other hand, developments to-date are frequently at odds with regulatory demands of purpose-specifications and meeting strict criteria of health technologies assessments, data protection and other matters with legal ramifications. Moreover, there are unresolved issues regarding the uptake and use of devices that are not strictly medical, but fit rather well into the wider discourse on health consciousness and self-tracking. Apart from the policy vacuum they emerge in, there are questions concerning the complexities in assembling and using gadgets, systems and supports devices remain unfamiliar and use scenarios uncertain, in spite of their cultural and marketing successes. There are questions of what to expect in terms of function, interoperability and infrastructural support, of the lack of purpose-specificity in many of the designs, of generalpurpose data capture, and more. One learning we draw from our investigations is to say that while new products are opening the doors to all kinds of users and uses, the business models typically rely on common denominators to trawl for data in numbers—to prescribe and exploit the traits and trends of behaviour that can be confined to structure, locality and kind for largescale commodification.

On the issue of *being in control* of one's performance toward health enhancement, the announcements and communication we looked at do not clarify in what sense exactly gadget-use enhances health in the long term. For example, most of the recommendations on how to be more healthy can well be put to practice without the assistance of a gadget like Fitbit. It remains unclear what precisely the data-relevancies are in designing these devices, apart from the allure of metrics, or what the expectations are of quasi-medical health enhancement use-purposes, apart from supporting media rituals of displaying responsibilized bodies and identities (Lupton, 2013). There are also situations using outdoor and endurance apps when gadget-use competes with physical performance for attention, in particular, when tracking or other recordings are not entirely reliable. Added efforts of managing recordings of physiological and behaviour data along with data on physical performance, beg the question to what extent self-tracking is technical labour with or without improvements of one's health.

The co-existence of medicine, leisure and the self-administration of care, blurs the boundaries between two legal regimes, that for medical devices and that for consumer devices.<sup>28</sup> One of the implications is that if smartphone-paired sensors for *health-as-leisure* are increasingly deployed for medical purposes, they come under pressure of being on par with and qualified as such. Similarly, the smartphone as an accessory to medically-graded sensors will have to satisfy stricter

<sup>27</sup> The withdrawal of Pfitzer's Rheumatology Calculator app serves as an early warning. See withdrawal letter at: <a href="http://www.swissmedic.ch/recalllists\_dl/05306/Vk\_20111019\_27\_e1.pdf">http://www.swissmedic.ch/recalllists\_dl/05306/Vk\_20111019\_27\_e1.pdf</a>.

<sup>28</sup> Also the *eHealth Action Plan* on this point (EC, 2012, pp. 9-10).

performance standards than currently apply. If this is what lies ahead, these devices and the services associated with them will have to be subjected to reimbursement schemes, raising questions to what extent (if at all) the publicly funded schemes take the burden, as opposed to the privately funded ones. Such developments will also call for standards on data formats and features of interoperability that enable users to switch between different products as they and their medical consultants see fit. From what we have learned, companies are not likely to engage each other in this direction of widely applied standards and interoperability without the promise of returns. If they are not already in the medical devices market which is very hard to break into in the first place, they are likely to stay in what is effectively a health-tainment market. But, this emergent co-existence has nevertheless complicated the broader picture of citizen responsibility and the question of where to draw the line between lifestyle and responsible patient behaviour.

We argue that the cultural and market successes to-date should be viewed primarily in reference to value creation which is rooted in cultural trends and traits, not the efficacy, improvement in healthcare delivery or cost savings promised in the eHealth Action Plan and the green paper on mHealth. The appeal to digital and media cultures resolves in a set of enticing interactional features and functions, in ritualistic acts and discipline, for the making of particular kinds of users who can relate to the instruments of mediation and exploit their affordances. It resolves in the making of particular kinds of citizens who emerge and are recognized as responsible and taking charge, in and through self-narration, knowledge co-creation and sharing. What is evident is that new business models are thriving on the fact that there is no legal framework with binding rules for quasi-medical products-who thrive on the principle of what has been termed 'the cost of free', to mass market data acquisition and gadget use, which to-date has escaped European regulation on data management and control. These models exploit the tension and ambivalence between desires to open up and hack the multinational and national control of medical instruments and data, the policy directives seeking more cost-effective and enhanced healthcare, the regulatory mechanisms to protect consumers and patients, and desires to exploit new data markets. The current model of health enhancement through the health-as-leisure markets tests the grounds of medical and data regulation and exploits the casting of citizens as responsible health consumers.

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