

“Self-management for better health? Reflections on the self-tracking culture”

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REPORT ON THE KEYNOTE BY BTIHAI AJANA

Introduction to the problematic aspects of the growing self-tracking culture (not only) in the health sector.

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The growing self-tracking culture is expected to be part of the solution to severe problems in the public health sector because it promises a personalised, participatory and preventive approach towards health. Even though there may be some benefits and positive outcomes of self-tracking, Btihaj Ajana’s keynote aimed to “caution against the excessive optimism towards the role and the potential of self-tracking technologies”.

SELF-TRACKING AND THE QUANTIFIED SELF

Self-tracking refers to the active gathering of everyday and health-specific data using smart technologies such as wearables and smartphones. The range of activities that can be tracked is immense and nearly endless: from sleeping patterns and exercise to sexual performance and eating habits. Almost everything can be measured and tracked. While any owner of a smartphone might consciously or unconsciously be tracking data in one way or the other¹, there is still a considerable difference from the self-tracking practices undertaken by the “quantified self” community, as Ajana pointed out.

The “quantified self” community is based on self-tracking but goes beyond this sole focus by being a proactive, organised and ideologically embedded culture that could also be described as a movement. Founded in 2007 by Kevin Kelly and Gary Wolf in the US, there are more than 200 groups in at least 34 countries that refer to themselves as quantified-self groups. They are characterised by a desire to improve various aspects of everyday life through quantification and numbers.

¹ For example, through the Apple Health App, which is pre-installed on iPhones and cannot be deleted.

BECOME BETTER THAN YOU ARE

What could be problematic about the idea of improving your own health or well-being through data accumulation? According to Btihaj Ajana, it is crucial to differentiate between those who already enjoy good health and aim to improve their fitness and those who suffer from certain diseases and use tracking devices to manage their condition and improve their health status. While the latter group seeks to cure or treat certain diseases (e.g. diabetes) the former is mostly driven by the promise “to become a better version of yourself”. For Ajana, the optimisation of the self is one of the central motives of the quantified-self movement. While at first glance, this could be regarded as a motivating and empowering outcome of self-tracking, there are several downsides directly connected to such self-improvement imperatives.

On the one hand, such developments represent a general shift of responsibility for health in society (Swan 2012). It appears that the healthcare system and its professionals are no longer the key actors responsible for health and wellbeing. It is instead the individual who has to become responsible, proactive and enterprising towards health and life in general. For Ajana, this attitude runs in “parallel with the decline of state support for social and healthcare programs in general” and is reflective of a pervasive neoliberal ethos.

EMPOWERMENT OR ABANDONMENT?

The seductive promise of empowerment and control over one's health might, in the long run, turn out to be no more than the abandonment of the patient, as the burden of responsibility and decision-making is left to the individual, according to Ajana. Additionally, the required technologies cannot be used without meeting further conditions. In fact, it is necessary to possess a certain “digital capital” as Ajana noted with reference to Hampshire et al.'s (2015) arguments. “Digital capital” refers to the need for appropriate resources, skills and social networks to take advantage of the potential of a digitally mediated healthcare.

And is it even desirable to know every detail about one's own body and health? Critics like Ajana argue that excessive knowledge could result in over-diagnosis and -treatment. If every little health issue is detected, this may result in an exponential increase in (unnecessary) treatment and an explosion of health costs. This runs entirely contrary to the promise of a more cost-effective health system through self-tracking (see Welch 2012). Moreover, it may result in increasing anxiety and stress for individuals rather than autonomy and control. Sociologist Deborah Lupton describes this phenomenon as “Cyberchondria”, a digitally enhanced version of hypochondria (Lupton 2013).

PUBLIC GOOD OR PRIVATE PROPERTY?

The discussion between those who advocate for the accumulation of health data and those who are sceptical about its benefits and outcomes is intense. Those who are in favour of the tracking culture regard their actions as a philanthropic contribution towards a humanistic goal: the promotion of a new type of medicine, individualised treatment and the cure of rare diseases. This is why the term data *philanthropy* was invented. The sharing of personal data is characterised as good citizenship that can contribute to a sense of public good. Furthermore, critics of data sharing are accused of being selfish and the whole concept of data protection as being egoistic (see also Ajana 2017).

Behind these terms of solidarity and betterment, Btihaj Ajana identifies something quite different. As the data are usually gathered by private companies, the concept of data philanthropy for public good turns out to be less romantic. The data are not accessible to the public and, what is more, not even to those who produce the data, as Ajana highlighted using the example of Fitbit and Strava. Fitbit, for example, used to charge 50 US dollars if consumers wanted to access their own data. So, what is promised to be a public good turns out to be a private property from which companies, rather than the public, benefit.

TRACK IT LIKE IT'S HOT (DATA)

Admittedly, the tracking of health data may have a positive impact on the treatment of certain diseases and especially for research purposes. For example, in the field of cancer research, hopes for better and faster curing rates through individual treatment is high. On the other hand, the tracking of sensitive health data may also result in undesirable outcomes: it may prompt a shift in responsibility towards the individual, the abandonment of patients, over-diagnosis and the privatisation of health data.

Thus, a public discussion is needed on the kind of data that should be gathered and what concept of health we are aiming for. If we're talking in terms of *public good*, it needs to be clarified who can access the data and for which purposes that data will be used. Then digitally mediated health may play an important role in the improvement of public health services.

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