Health-tracking technologies: from the quantified self to a public health tool?

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HEALTH-TRACKING TECHNOLOGIES: FROM THE QUANTIFIED SELF TO A PUBLIC HEALTH TOOL?

PROF. MELANIE LEVY – HEALTH LAW INSTITUTE – FACULTY OF LAW – UNIVERSITY OF NEUCHÂTEL – 26 MAY 2021
THE “SILENT” PANDEMIC OF NON-COMMUNICABLE DISEASES

- Today more people die from cancer, heart disease, and diabetes than from infections, famine, and pregnancy complications worldwide except sub-Saharan Africa.
- For the first time in decades, general life expectancy in the developed world is declining.
- Chronic non-communicable diseases (NCDs) linked to population diets, consumption patterns, and physical activity have replaced the threat of infectious diseases (before COVID-19!).
- These diseases place a significant cost burden on a country’s economic productivity and public healthcare system.
The five major insurance companies in Switzerland have started monitoring the health behavior of their insured through health-tracking devices.

Motivational mechanism: financial incentives (e.g., premium reductions, rewards, cashbacks) are offered for using health-tracking devices, sharing the data, and achieving preset goals such as a certain number of steps a day.

Idea: healthy behavior is rewarded, but only under the condition of surveillance and control through health-tracking technology and data sharing.
OUTLINE

- The technology: wearables and other digital health products
- The quantified self
- Digital public health: connection between technology and health promotion
- Health insurers as health promoters?
- Impact of health-tracking devices on health outcomes
- What’s law got to do with it?
- Conclusions
THE TECHNOLOGY: WEARABLES AND OTHER DIGITAL HEALTH PRODUCTS
A FEW FACTS

- Wireless mobile devices and software monitor and measure bodily functions, activities, and geolocation: heart rate, walking distance, steps, stairs, calories, sleeping pattern, etc.
- Data can be filled in manually (e.g., picture of food intake) and then shared; there is also real time measuring and transmitting of data.
- Great potential for disease prevention and health promotion: health behavior change through digital motivation and gamification.
- The number of connected wearable devices worldwide has more than doubled in the space of three years, increasing from 325 million in 2016 to 722 million in 2019. The number of devices is forecast to reach more than one billion by 2022.
THE QUANTIFIED SELF
DEFINITION: THE QUANTIFIED SELF

- Individuals perceive their health more and more through data: self-knowledge through numbers.
- Desire to have one’s health tracked and evaluated by means of continuous empirical measurements.
- Health-tracking devices allow individuals to engage in self-tracking (empowerment!).
- Increasing obsession with self-optimization.
- The “motto”: self-responsibility through self-management.
- Do-it-yourself health promotion, through self-quantification!
DIGITAL PUBLIC HEALTH
## USE OF HEALTH-TRACKING DEVICES TO PROMOTE HEALTH

<table>
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<tr>
<th>Technology</th>
<th>Individual &amp; Society</th>
<th>Digital public health</th>
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<tr>
<td>- Wearables and other digital health products</td>
<td>- The quantified self</td>
<td>- How to incorporate self-tracking technologies in public health promotion and preventive medicine?</td>
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<td>- Which public health actors?</td>
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USE OF HEALTH-TRACKING DEVICES TO PROMOTE HEALTH

State
(protect public health against NCDs; slow down public spending)

Individual
(quantified self; self-optimization)

Health insurer
(incentivize healthy behavior to avoid future costs caused by NCDs)

Health professionals?
HEALTH INSURERS AS HEALTH PROMOTERS?
<table>
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<tr>
<th>App’s name</th>
<th>Type of data shared</th>
<th>How is data shared?</th>
<th>Rewards for data sharing</th>
<th>How can rewards be used?</th>
<th>Who benefits?</th>
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| Helsana [22, 23]            | Health-related behavioural data of routine activities (e.g. steps) or time-limited activities (e.g. sport event) | 1. Automatically: by linking health apps (e.g. Google fit), or fitness trackers (e.g. Garmin) to the insurance app  
2. Manually: by sharing photos or scanning QR codes. | Redemable bonus points: the amount depends on the insurance cover, and is limited per year (30,000 for AHI and 7,500 for BHI) | Bonus points can be redeemed as cash, benefits in kind, or vouchers. Up to CHF 300 can be redeemed per year. | Insured people. Even under-age individuals from the age of 12 can participate upon authorisation by legal representative. |
| myCSS (MyStep option) [24, 25] | Number of steps per day.                                                            | 1. Automatically: data from a fitness tracker is synchronised with the app.          | Cash credits: CHF 0.40 for every day with 10,000 or more steps; CHF 0.20 for every day with between 7500 and 9000 steps. | Credits are paid as cash to the insured person. Up to CHF 140 (365 days at CHF 0.40) can be redeemed. | Insured people with AHI. However, behavioural data is compared with data concerning BHI of the subscriber for marketing and statistical purposes. |
| Sanitas Active [26, 27]     | Personal data, data about nutrition, sleep, pulse, and other routine activities (e.g. steps, minutes of cycling). | 1. Automatically: by linking health apps (e.g. Google fit), or fitness trackers (e.g. Garmin) to the insurance app. | Coins: the rewards depend on the achievement of daily targets or the completion of challenges. | Coins can be redeemed as vouchers to be spent with one of partner companies. Collected credits cannot be exchanged for cash. | Insured people with additional insurance.                                                                                             |
| Swiss BENEVITA [28, 29]     | Data concurring lifestyle habits and data from fitness trackers.                    | 1. Automatically: data from a fitness tracker is synchronised with the app.          | Bonus points: depending only on the declaration, a specific amount of points is granted. | Bonus points determine the status of the user and the entitlement to a premium discount up to 15%.                                   | Insured people.                                                                                                                           |
| SanaHealth [30–32]          | Data concurring physical activity, eating habits, heart rate, blood pressure and sleep patterns. | 1. Automatically: data from a fitness tracker or health app is synchronised with SanaHealth.  
2. Manually: the person feeds single pieces of information. | Redeemable bonus points. | Bonus points can be used in a user-reserved shop (“SanaHealth-Shop”) to buy a series of products. | Insured people. The app is currently being developed as a pilot project limited to 1500 participants. |

Source: Martani et al., 2019
Health-tracking devices are part of a bonus system to engage insured individuals through incentives. There are two aspects here:

1) Financial rewards encourage healthy behavior by providing a tangible and short-term benefit (i.e., lower insurance premiums in exchange for responsible behavior and data sharing).

2) Long-term expectations of positive health outcomes (i.e., fewer individuals requiring care for NCDs such as obesity or diabetes).

This connection between public health and health insurance is so far mostly unprecedented in the Swiss health system. Historically, health promotion has not played a substantial role in the conceptual and legal framework of health insurance.
Health-tracking devices offer surveillance and discipline of a controllably healthier way of life!

State/Insurance imposed individual responsibility for healthy behavior.

It is not only about responsibility towards oneself, but society. Healthy behavior of the individual is in the interest of social security (i.e., slow down increase in health insurance premiums) and public finances.

The goal is to guarantee the sustainability of the healthcare system facing intense pressure caused by chronic NCDs (collective interest!).
IS TRACKING AND REWARDING INDIVIDUAL HEALTHY BEHAVIOR BY HEALTH INSURERS AN ADEQUATE TOOL TO PROMOTE PUBLIC HEALTH?
IMPACT OF HEALTH-TRACKING DEVICES ON HEALTH OUTCOMES
LIMITED EMPIRICAL DATA SO FAR

- Effect of financial incentives on individual intention to subscribe to data-driven health plans?

Presence of financial incentives plays a significant role in the uptake of health tracking devices and the sharing of data with health insurers (Stepanovic/Mettler, 2020; Mettler/Wulff, 2020)

- Do financial incentives for the use of health-tracking devices produce meaningful cost savings and individual quality of life improvement?

Little is known so far about the long-term effect of health-tracking devices. Usage of IT devices and services tend to diminish with time!

- More empirical studies necessary, e.g., risks linked to technostress and cheating (“free rider”).
IS TRACKING AND REWARDING INDIVIDUAL HEALTHY BEHAVIOR BY HEALTH INSURERS AN ADEQUATE TOOL TO PROMOTE PUBLIC HEALTH?
WHAT’S THE LAW GOT TO DO WITH IT?
DATA PRIVACY, TRANSPARENCY, AND SECURITY
THE VALUE OF DATA!

- Health insurers have a vested interested in analyzing the health-related behavior of their customers.
- Using big data to generate insights into health behaviors and links to disease (AI!).
- The supposed “precision prevention” approach that large data sets will offer to health promotion efforts (profiling!).
- Economic value of data gathered for third party users (surveillance capitalism!).
- Commercial use of health data gathered?
Fundamental principle of legitimate data usage: clearly defining the purpose for which data is collected and shared, in particular regarding sensitive information such as health data.

Importance of clearly disclosing the purposes of data processing, at the moment when consent by data subjects is obtained and data is shared.

Data use after consent? General consent (including future use)? “Blind consent” to T&C?

In health insurers’ data-sharing apps, the entire range of purposes for which users’ data is processed is not equally disclosed. The common message that the insurers promoting their apps deliver is that the key purposes of data sharing are the following: (1) improve individual health; (2) help users save some money (Martani et al., 2019).
CRITICAL QUESTIONS

- T&C to use health insurers’ apps specify that the purposes of data collection also include more delicate aims, such as using data for marketing purposes and forwarding data to third parties (Martani et al., 2019).
- If it's free (or if you are financially incentivized to share data), then you are the product?
- Is there really a link between using health-tracking devices, beneficial health outcomes, and cost savings? Maybe the goal is not to promote the health of users directly, but to collect valuable health data?
SOLIDARITY
Solidarity is a fundamental pillar of our healthcare system and social health insurance system (i.e., solidarity with sick patients, who get access to treatment unrelated to their financial means).

In health prevention and promotion, the notion of solidarity changes!

Solidarity through individual responsibility:

Solidarity with taxpayers and health insurance premium payers, by increasing individual responsibility for healthy behavior and thus avoiding unnecessary costs caused by non-communicable diseases.

Solidarity through data sharing:

“Data donation is the new blood donation”, says Roche Board Chairman C. Franz in a recent interview. He emphasizes that a new sense of community is needed: ... providing data, a service to society!
Singling out people based on their individual behaviors and lifestyles violates the principle of solidarity.

People who choose to smoke, or to eat unhealthy, compromise solidarity by potentially incurring higher costs for the collective.
EQUALITY AND NON-DISCRIMINATION
Article 8 Swiss Constitution

1 Every person is equal before the law.

2 No person may be discriminated against, in particular on grounds of origin, race, gender, age, language, social position, way of life, religious, ideological, or political convictions, or because of a physical, mental or psychological disability.
<table>
<thead>
<tr>
<th>Health inequalities</th>
<th>Financial inequalities</th>
<th>Digital inequalities</th>
<th>Privacy/Autonomy</th>
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<tr>
<td>• Health literacy depends on socio-economic status.</td>
<td>• Health insurance premiums are a financial burden.</td>
<td>• Many individuals struggle with access to digital technologies or simply fail to see a reason to use them.</td>
<td>• Individuals who have a healthy lifestyle, but refuse to share their data through insurers’ apps, perhaps because of concerns related to data protection?</td>
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<td>• Older people and people with a health problem who cannot achieve the required number of steps.</td>
<td>• Socio-economic background of individuals giving access to their health data to receive a reward and pay less for their insurance premiums?</td>
<td>• Internet use is correlated not only with age but with income, education, and geographical location.</td>
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WHAT ABOUT SOCIO-ECONOMIC DETERMINANTS OF HEALTH?

- Health-tracking devices and their application in health promotion push a liberal approach of individual responsibility for healthy behavior.
- If health is “feasible” and the result of individual behavior, then those who get sick are at their own fault.
- The claim that discrimination based on lifestyle choices is justified because behavior is voluntary, rational, and a matter of free choice is highly doubtful.
- Unhealthy behavior is often associated with socio-economic determinants of health over which the individual has little control.
- NCDs caused by poor diet and lack of exercise are most common amongst the least well-off in society.
CONCLUSIONS
CONCLUSIONS

- Potential of public health digitalization and technologies such as health-tracking devices.
- The major differences offered by these new technologies - compared to traditional health promotion tools - are the continual nature of the surveillance opportunities they present, their expansion into the intimate sphere of sensitive health data and the commercial value of the data they collect on people’s health-related behaviors as part of the digital data economy.
- Financial incentives for a controllably healthier way of life! Surveillance and Discipline!
- How far should privacy, self-determination, and data protection in health promotion become something that one “has to be able to afford”? 
THANK YOU FOR YOUR ATTENTION!

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SNSF ECCELLENZA-PROJECT:
THE INCREASING WEIGHT OF REGULATION: THE ROLE(S) OF LAW AS A
PUBLIC HEALTH TOOL IN THE PREVENTION STATE

OUR TEAM: