Placing Citizens with their Health Data at the Center of a Changing Global Healthcare System

Improving Health and the Personal Data Economy by Linked National Cooperatives as Citizen-Owned and Citizen-Controlled Personal Data Platforms

1. The Challenge: Citizens cannot Benefit from their Health Data as it is stored in Silos

First, citizens (both individuals with medical needs and healthy persons) legally own their health data. Since they lack access and control over such data, they cannot use the data to its full benefit. Furthermore, the move towards personalized prevention and healthcare requires large complex datasets from millions of people. These cannot be obtained without the active participation of citizens across the world.

Second, health data are stored and controlled by physicians, hospitals, labs, pharmacies, insurance companies and government agencies in innumerable, incompatible data silos. The quantity and complexity of this data is rapidly expanding, from innovations such as mobile apps, sensor and tracking devices, and affordable genome sequencing. This dysfunctional – and unsustainable – data model substantially increases the cost and reduces the quality and effectiveness of health care globally.

2. The Solution: Empowering the Citizens by Giving Them Control over Their Data

Cooperatives. Cooperatives are an old and successful form of corporations that are entirely owned by citizens. The DNA of the cooperative is "We do it ourselves, on our own terms, self-supporting; rather than depending on government or pure capital investors. In many countries we see successful cooperatives in the form of retail stores and banks to name just two examples. Since all data in health are personal and each citizen (whether from Europe, North & South America, Asia, Africa or Oceania) has about the same amount of health data (i.e. same genome size), the one-member-one-vote principle for a health data repository is particularly well suited. Members who join the cooperative will safely store and manage all their health data (medical, mHealth, genome, etc) in their account. In this way, they have access to all their data from anywhere in the world and they can share subsets or all their data with doctors, friends or biomedical research. Since citizens are the owners of their data, their informed decision to share their own data for research is not subject to the same data protection regulations as when third parties request to access personal health data.

Aggregated personal data have a large economic value (estimated to reach € 1 trillion in 2020 according to a BCG report). Thus pharmaceutical companies and other research institutions will pay significant sums to query the data that users have consented to share. The revenues will stay in the national cooperative and members decide whether to invest the gains into research, information platforms or continued education. Being in control of all their data and deciding how capital gains will be used for the common good represents true
citizen empowerment and unleashes the large potential of aggregated health data for personalized prevention and treatment.

Setting up a federation of national health data cooperatives that share the same IT infrastructure and central data storage in Switzerland would result in a true democratization of the global health data space and will directly benefit the national communities of citizens.

3. The Health Data Cooperatives – A Democratic Movement to Reform Healthcare, Stimulate Research and the Economy

As outlined above, the realization of a more personalized healthcare focusing on personalized treatment and above all personalized prevention is becoming possible because of technological advances in biomedical research (genomics etc) and mobile health monitoring. For it to result in better individual and global health, however, the citizens will have to change from passive recipients of care to active agents in the system by taking control over their most valuable and personal asset, their own health related data. Such a process cannot be ordered by governments. It has to have its origin in a bottom-up, democratic movement, since not every citizen will be ready to seize this opportunity and responsibility at the same time.

Such a citizen-driven movement to obtain control over one’s own health data will have direct health and economic benefit for each country providing that a significant fraction of the population engages in this movement. The primary benefits for the individual are that his or her data are readily accessible thus preventing secondary tests and better informed diagnosis. Providing that citizens actively provide their anonymized data for clinical outcomes research and biomedical research, there will be economic benefits to the healthcare systems. It is estimated that approximately 30 percent of the total healthcare costs are caused by inefficiencies owing, to a large extent, to the inaccessibility of data.

Given the economic value of aggregated personal data and health data in particular, the national personal data cooperatives owned and directed by its citizens would act on behalf of and for the benefit of the citizens to obtain the full economic value of these data and to invest the revenues according to the citizens decisions into research, education, or better services.

4. Outlook: Citizen-owned Personal Data Platforms will Successfully Compete with Multinational Shareholder-Value Driven Companies in the Emerging Personal Data Economy

As for health data, each person on the planet has similar amounts of personal data. The value and the challenges lay in the aggregation of different datasets of millions of persons over time. Individuals will consent to the aggregation of the data if it is to their own benefit and that of society and does not cause harm. Cooperative personal data platforms will stimulate the rapidly growing data economy by allowing third parties to develop services for these platforms (data aggregation, visualization, data query, information and knowledge generation) since they offer (with the citizens’ consent and for the citizens’ benefit) the largest possible span of integration (from social media, nutrition, geo-location, health and genome information). Importantly, in this model the decision what data to share with whom is always with the citizens. They are in control.

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