



5th Newsletter of the Association Data and Health

February 2017

Dear members

#ewn1 is our hashtag for "es wird nie langweilig" (it never gets boring). This Swiss understatement is certainly true for 2017 with the forthcoming revision of the Swiss Federal Act on Data Protection (FADP), the implementation of the Federal Act on the Electronic Patient Record (EPRA) and the work on the revision of the Federal Act on Research involving Human Beings (Human Research Act, HRA). The aim of our association is, among other things, to help citizens to increase their control over the use of their health data and to empower them to use and manage them as they wish. In the above-mentioned activities of the Confederation, however, we are disappointed at how little confidence the government places in the maturity of its citizens, and at how the government seems disinclined to strengthen the data sovereignty of the inhabitants of Switzerland.

Although you have not heard or read much about us in the past months, we have been active. With this newsletter, we want to inform you about past activities and show what we are working on and where we need your support as members of the Data and Health Association.

Control of personal data - the Right to a Copy

At the General Assembly of our association in January 2015, Prof. Thomas Gächter presented the working document "Right to a Copy". This right is intended to give each person the right to receive a digital copy of their personal data in an adequate form (shopping data, health data, educational data, etc.). The person itself can decide about any further use of his/her data (secondary use), e.g., to obtain a second opinion by a doctor, to provide the data for research purposes, or to share the data with friends. After numerous discussions with parliamentarians, we succeeded in prompting a postulate, which called on the Federal Council to examine the introduction of the Right to a Copy. The postulate was transmitted at the request of National Councilor Fathi Derder. As early as November 12, 2015, the Federal Council adopted this postulate with the promise to examine its usefulness within the framework of the forthcoming revision of the Data Protection Act. In the draft consultation on the law, which was published shortly before Christmas 2016, data portability, a requirement of the European Data Protection Regulation, was provisionally excluded. Data portability, and possibly a Right to a Copy, is to be dealt with only at a later date (see also the mention of us in https://en.wikipedia.org/wiki/Data_portability).

The board of the "Data and Health" Association is disappointed by the hesitant attitude of the federal administration in this matter because we are convinced that Switzerland has a great opportunity to play a pioneering role in the global digital society. We see the Right to a Copy as a central instrument to strengthen citizens' informational self-determination and to empower them to take responsibility for their data.

Citizens' control over the secondary use of their data (made possible by their Right to a Copy) is a prerequisite for many new forms of data economies: The collection, integration, storage and sharing of data from different sources (service providers, smartphone, purchasing, geolocalization, mobility) comprises the basis for not only new types of research projects, but also completely new services.

As a further important element in addition to the "Right to a Copy", the "Data and Health" Association is committed to the creation of health data cooperatives. While the "Right to a Copy" sets the legal framework for control of the secondary use of one's own data, data cooperatives provide the operational implementation of this control.

We have published our views in two opinion pieces in the NZZ ("[Befreiung aus der Digitalen Leibeigenschaft](#)" and "[Meine Bildungsdaten gehören mir](#)"). Two scientific papers, among others, in collaboration with Prof. Francis Cheneval (UZH, political philosophy), are currently under review. They show how the democratic control over the secondary use of personal data creates the prerequisite for a property-owning democracy, which has been described by John Rawls as the most equitable form of government.

Establishment of data cooperatives

Just as in other sectors, there are different models for storing and managing personal data. Users can decide for themselves which models suit them best. Members of the association have established two data cooperatives with different business models: in 2013 the cooperative Healthbank and in 2015 the cooperative MIDATA.

Healthbank:

Healthbank pursues a for-profit model and launched its platform in September 2016 at <http://www.healthbank.me/>, where an account can be opened and medical data can be uploaded. Further information on Healthbank can be found on the [website](#) of the cooperative.

MIDATA:

MIDATA pursues a not-for-profit business model that neither provides financial incentives for data sharing nor pays dividends to its members. The members decide how profits are to be invested, whether in services offered on the platform or in research projects.

Being developed by teams of the ETH Zurich Systems Group and the Institute of Medical Informatics at the Bern University of Applied Sciences, the MIDATA platform was put into operation in May 2016 following independent safety audits for an initial pilot project with the Insel-Spital in Berne. Further information on other projects can be found on the [MIDATA.coop](#) website. The development of the MIDATA platform and

the first pilot projects are tentatively funded through research contributions from ETH Zürich and other institutions. MIDATA also has obtained an interest-free loan from the Think Tank M1.

In Switzerland, six pilot projects will be launched in the coming months (in the areas of Citizen Science, Diabetes, Multiple Sclerosis). In addition, internationalization is being promoted. Concrete plans to implement a national MIDATA platform exist in Holland (Medical Delta and TNO) and in Germany (Berlin Institute of Health and Charité). In cooperation with the Swiss Tropical and Public Health Institute and the organization INDEPTH-Network.org, platforms are also to be established in Ethiopia and in Vietnam.

Outlook for 2017

Right to a Copy

One major task is to discuss the right to a copy within the framework of the consultation on the Data Protection Act. To this end, we have teamed up with Opendata.ch. Together with further stakeholders we plan to form a Swiss Data Alliance, which will address the questions of connection and use of the public data as well as control over one's personal data (Right to a Copy). In cooperation with the Bern University of Applied Sciences and the Center for Digital Society, the association is organizing a workshop on the social value of the control of the personal data in March. This project is supported by the Swiss Academy of Engineering Sciences. We are also reviewing the launch of a popular initiative to bring the Right to Copy into the Swiss constitution. Switzerland would thus be the first country worldwide to explicitly enshrine such a right in its constitution. We would play a pioneering role here.

Data and Health Association

We plan to hold the General Meeting in the second quarter of this year. We would like to take the opportunity to renew our board of directors and at the same time organize an information event on the right to copy. We would be pleased to receive offers from our members to help launch specific projects with our association.

NOTES

- Do you want to find out about the association and its health data projects? Visit the [association's website](#).
- Would you like to discuss talk with other members about current controversies surrounding data and health? Use the discussion forum on the our [Wiki Platform](#). As a member please [request access](#) to the platform.
- Do you have feedback or suggestions for this newsletter? [Sign up with us](#).
- Do you want to join the Association Data and Health or to (un)subscribe to the newsletter? [Contact us](#).

ASSOCIATION DATES AND HEALTH

The association focuses on the development of social, ethical, political, legal and scientific framework for the creation of a co-operative Swiss data and biobank for safe collection, storage and use of personal health data and biological material from around the world.

