



## 2nd Newsletter of the Association Data and Health

June 2014

### AT THE CUTTING EDGE OF THE PERSONAL DATA REVOLUTION

"To develop and spread ideas don't be a star be a galaxy!" says Dr. Peter Gloor from MIT's Center for Collective Intelligence in his lecture "The Stupidity of the Crowd and the Wisdom of the Swarm" held in mid April. The lecture was organized by the Association Data and Health and the Think Tank W.I.R.E. About 40 people came together and discussed intensely. If you missed the lecture you can download the slides of the presentation on our website.

### THE ASSOCIATION IN THE MEDIA

**"It takes a cultural change, so that citizens can take over the control over their data," says Ernst Hafen in [Beobachter interview](#) on "The quantified health".**

The article published in May is asking about ownership rights of datasets and the (non-) sense of health apps. In particular, two Swiss efforts in the Data Management are presented: The electronic patient record proposed by the federal government and the health data cooperative model proposed by the association Data and Health. Ernst Hafen argues that large numbers of individuals have to actively participate with their data to advance personalized medicine. Citizens must realize that their data has a value ("when it comes to personal data we are all billionaires") and that they themselves can manage the usage of their data ("like your own money").

### SCIENTIFIC PUBLICATIONS BY MEMBERS OF THE ASSOCIATION

**Of the more than 1,000 students at the University of Zurich and ETH that [responded](#) to a survey whether they would order a genome analysis for themselves, 59% said yes. The main reason the students gave was to contribute to biomedical research with their data.**

Direct-to-Consumer Genetic Testing is currently prohibited in Switzerland. However, citizens use appropriate offers in other countries. The Expert Commission on Genetic Studies in Humans (GUMEK) suggests a revision of the law to ensure that such services can also be offered in Switzerland and so the

quality can be assured. The survey among students - who come mainly from the natural sciences direction - shows that in most cases the interests in participating in research is weighted higher, than obtaining information about personal risk factors. In addition, the main reason for those 41% that would order such analysis is that they do not want to receive genetic information about possible risks.

## INITIATIVES IN SWITZERLAND

**Member of the parliament Barbara Schmid-Federer refers to the recommendations of the Technology Assessment Group ([TA-SWISS](#)) study and proposes to the Federal Council to consider to establish [a national biobank](#).**

"It would make sense to build a national biobank," it says in the study on personalized medicine by the Centre for Technology Assessment TA-SWISS published in 2014. At present, mainly foreign private "direct-to-consumer" genetic testing companies are gaining from personal health data - even in domains (e.g. genomics) that run counter to current legal regulations in Switzerland. Based on these results Barbara Schmid-Federer filed an interpellation in the National Council in early May. She asks whether a national biobank would not be in the interest of Swiss biomedical research and proposes in this context further measures such as SNF support programs and laws adjustments. Member of the managing board of Data and Health Vincent Moser together with others plans a correspondent national biobank and are currently realising a [pilot](#) in Lausanne.

## INITIATIVES ELSEWHERE

**The European Commission wants develop the full potential of electronic devices and services in the health sector by a [public consultation period](#) on mHealth.**

Increased prevention, self-determined patients and a huge market potential - Body sensors and devices offer huge potential. On the other hand, open questions about safety standards, ethical Big Data use and effectiveness in the use of healthcare remain. In the "Green Paper on mobile health", the European Commission gives an overview of the ambiguity and invites all interested parties to provide feedback. Contributions will be collected until 3 July and published on the website. D&H member Thomas Ruddy has provided an input to the attention of the European Alliance for Personalised Medicine EAPM - [Collaboration via the Wiki Platform of D&H](#) is encouraged.

## LEARNING FROM OTHERS

**What should be done with the personal education data of the higher education and career planning portal ConnectEDU after it has gone bankrupt? An [article the New York Times](#) depicts the case.**

Stormy times for the US data protection lobby: The student site ConnectEDU went bankrupt in April and is about to sell-off millions of students names, dates of birth etc. "This is a breach of the company's Privacy Policy", states the consumer protection advocate Jessica L. Rich in mid-May. ConnectEDU should, recommends Mrs. Rich, allow registered students to delete their data prior to a sale or even better to decide to delete all the personal data on its own initiative. Parallel to this scandal, two well-known federal senators announced to try to allow students and their parents by a change of law more control over the handling of their personal school data. Much like health data, education data are personal, sensitive and extremely valuable.

## RECENT STUDIES

**Swiss citizens view the introduction of electronic patient records positively. This shows a representative [telephone survey](#) of [comparis.ch](#).**

Nearly two thirds of respondents of the February 2014 survey are in favor of electronic patient files, the introduction of which are currently discussed in Parliament. Most commonly, the quick access to information is cited as the main advantage of a digital file. 57 percent would create such a file for themselves. Most respondents have concerns because of a possible misuse of data (63 percent of responses). Nevertheless more than 50 percent feel that the benefits of an electronic patient record outweigh the risks. In addition to the patients themselves 82 percent of the respondents posit that the family doctor should have access to the data, for 21 percent health insurance companies should also have access. A slim majority considers the financing of the electronic patient record a duty of the state, 16 percent feel that this is the task of the patient him- /herself.

## 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? Do you want to publish a guest post? [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.