

# The therapeutic potential of health data

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Credit: Swiss National Science Foundation

In the future, doctors won't be concerned about treating just a diseased organ – they'll be using a mass of data to get a holistic view of the state of their patients." This is how the Swiss Centre for Technology Assessment describes the dream of personalised medicine. In this scenario, drugs will no longer be prescribed only according to a diagnosis, because gene variants and self-generated data will be consulted before decisions are made.

The Scandinavian countries, the EU and the USA have all set up research initiatives in the field of personalised medicine. And now Switzerland wants to do the same. In its ERI Dispatch of February 2016,

the Federal Council granted CHF 70 million over four years for a 'Swiss Personalized Health Network'. The Swiss Academy of Medical Sciences (SAMW) is supposed to coordinate the many current local initiatives at universities and hospitals and enable the exchange of the extant [data](#).

"It's only this large network that will enable us to realise the potential of [big data](#) in the field of health," says Hermann Amstad, General Secretary of SAMW.

This wealth of [information](#) is supposed to enable doctors to find the most effective treatment with the fewest side-effects. The drug ivacaftor, for example, only works for people with a special variant of the hereditary lung disease cystic fibrosis. And the duration of the expensive drug courses needed to treat hepatitis C can be shortened according to the gene variants of the people affected.

## Unhealthy expectations

But let's clear up a misunderstanding from the start: medicine has always been personal. The present endeavour is just about adapting therapies to specific characteristics. For this reason, people often talk about it as 'precision medicine'. But the path to personalised medicine is a stony one. The biggest hurdles to it include vested interests, [data security](#) and the question of how to implement the concept in a practical context. There are sceptics – such as Timothy Caulfield, a Canadian professor of health law and policy, who warns about raising false hopes: "There is little reason to suspect that the promised cost-saving, life-extending, population- health-improving revolution will unfold as suggested by [its] many vocal advocates."

## The four pillars of personalised medicine

New treatments need to integrate genetic information, samples and

measurements that were collected by patients themselves. Behind this are efforts to standardise and open access to databanks.

Estonia was the first country to do it, back in 2008. And in Switzerland, Geneva was the first canton to allow its citizens electronic access to their patient files, as of May 2013. According to 'Strategie eHealth Schweiz', this should be made possible for everyone in Switzerland in future.

Research can also profit from electronic patient files. Whoever agrees to it can give researchers access to their medical history and their data in biobanks. This can allow retrospective studies into what treatment was the most effective for which group of stroke patients. The British psychiatrist and author Ben Goldacre dreams of large-scale clinical studies in which doctors can try out new therapy variants as a matter of course.

There are all kinds of technical, legal and ethical hurdles to surmount before reaching that point, however. Torsten Schwede of the Swiss Institute of Bioinformatics is in charge of the Swiss data coordination centre, and in his opinion the data still has to be harmonised. "If a file in Basel mentions a 'fever', that might not necessarily correspond exactly to the concept of 'hyperthermie' at the University Hospital in Lausanne. It's difficult to find a common language for internal medicine and ophthalmology even within the same hospital."

## **Cohort surveys: Comparing medical histories**

a combination of three different antiretroviral drugs – and sometimes these can have drastic side effects. For example, the drug abacavir can cause a life-threatening drop in blood pressure and a high fever in very small numbers of patients. If they are tested for the gene variant HLA-B\*5701 before being given the drug, such emergencies can be avoided.

This gene variant is a so-called biomarker that allows the HIV therapy to be personalised. Further markers can also provide measurement data or information about a patient's lifestyle. In order to find such biomarkers, cohort surveys are necessary. These are studies that systematically track a large number of patients from different groups over long periods of time.

The Swiss HIV cohort survey has been running for 28 years. Blood samples are taken from 10,000 patients every six months and stored in the survey's own biobank. Huldrych Günthard of the Zurich University Hospital is the head of this survey, and he says such cohorts provide the basic data that is essential for personalised medicine: "Specific diagnoses in hospitals are sometimes distorted by economic factors, such as codifying invoices according to flatrate payments. In the cohorts we have precise medical histories and a huge amount of laboratory data."

## **The quantified self: Patients monitoring themselves**

A smartwatch records your sleep rhythms, while a sensor integrated in an undershirt constantly monitors your blood sugar level. In the evening, all the data is uploaded to a social platform where diabetics can exchange information on their experiences. A tap of the finger on a tablet computer copies the data into your electronic patient file. When you see your doctor, you can discuss this self-generated data along with the treatment options that an algorithm has automatically recommended for you.

This is the vision of Ernst Hafen, a molecular biologist at ETH Zurich who is promoting personalised medicine in Switzerland. "It's essentially a Google map of health. Instead of having geographical information according to longitude and latitude, the [medical data](#) of the individual should be integrated in it."

Hafen's vision sounds utopian in several aspects. But initial steps towards it have already been made. There is no lack of self-tracking apps. And sufferers of ALS (Lou Gehrig's Disease) have come together on the web platform 'PatientsLikeMe' and have already published their own study on the non-effects of lithium carbonate. The University of Basel is currently carrying out a study using step counters in order to investigate the influence of movement on cancer therapies.

## **Biobanks: Slumbering samples in biobanks**

Research groups and university hospitals have long been collecting and storing samples of DNA, blood and tissue. When linked to a patient's medical history, these form the backbone of personalised medicine. However, most biobanks are geared to the needs of the individual institutions where they are housed, without anyone having considered how to provide access to other researchers.

Christine Currat estimates that some 300 biobanks, big and small, are currently in existence in Switzerland. Currat is the manager of the 'Swiss Biobanking Platform' (SBP) that was founded in April 2016 and is being supported by the SNSF. It is intended to provide researchers with access to all the valuable information that has already been collected across Switzerland. "I would first like to make a list of the extant biobanks," says Currat. Her main goal is to harmonise procedures so that samples and the information linked to them can be exchanged more easily.

"We need a unified declaration of consent for patients and, above all, we need documentation about how the samples were taken and stored," says Currat. In the long term, the SBP intends to provide researchers with an entry platform to the different biobanks – not just for medical purposes, but for biological research as a whole.

## The problems with new medicine

There are all kinds of stumbling blocks on the way to personalised medicine. Two particularly big obstacles are dealing with confidential data and transferring findings into practice.

### Data security: Networking personal data is a delicate matter

Genome data doesn't just offer information on personal characteristics and risks. It also allows you to draw conclusions about the situation of relatives. This is why such data is subject to a high degree of legal protection. And the Swiss Centre for Technology Assessment is recommending extending this protection to all [personal data](#). Just how important it is to maintain the trust of the population is proven by the UK programme for linking all clinical data within the National Health Service. After public criticism was aired because of the re-utilisation of data, the programme was halted for a year in 2014.

Ernst Hafen, a molecular biologist at ETH Zurich, has a clear opinion on this: "Only the individual has the right to place his or her data at the disposal of others." His association 'Data and Health' is insisting on digital sovereignty.

However, this does not solve the problem of anonymisation. Even if a single cholesterol measurement cannot be traced back to an individual, when it is linked with lots of other data, that person may still be identifiable. "The only data that may be made available is the data that is necessary for the research project in question and whose use can be agreed with the patient," says Torsten Schwede of the Swiss Institute of Bioinformatics. And the researchers must work within a secure research platform where sensitive data is encrypted. This has already been done

for genome research projects.

Brigitte Tag, a professor of law at the University of Zurich, would most of all like to see a secure legal framework on a national level:

"Collecting, storing and processing data for human research should be regulated in a uniform manner. The researchers too will profit from this."

## **Scepticism about evidence-based medicine: The impenetrable jungle of medical data**

When progress was being made in evidence-based medicine, "something of the art of medicine [was] lost," wrote Joseph Fins recently in the specialised journal *The Hastings Center Report*. Fins is a professor of medical ethics and medicine at Weill Cornell Medical College. His hesitation is also found elsewhere: a survey carried out by Cochrane Switzerland in 2015 found that every fourth general practitioner admitted that evidence-based medicine is of limited use. Gerd Antes, the Director of Cochrane Germany, told the TV channel 3Sat back in 2015 that he wasn't surprised by this: "Researchers are thinking of their careers, companies about their profits, and the doctor stands somewhere between them and is being falsely informed by both sides."

The evidence base in medical research is very confusing. Near- identical clinical studies are being repeated over and again, roughly half of all studies are never published, and the flow of information from research into practice is badly organised. The result is either an excess of medical information or a shortage of it. With personalised medicine, the jungle of data will only become even more impenetrable for doctors.

Bernard Burnand, the Director of Cochrane Switzerland, says: "We need a markedly better information system." In its 2014 report, the Swiss

Centre for Technology Assessment also recommended that interpreting data be given greater emphasis when training doctors. Burnand sees a danger for research here: "The regulations for clinical tests are going to get even stricter. What we still lack today is a means of scrutinising therapies in a practical setting."

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