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'Without data, there can be no advances in research'

Personalised health from the public health perspective will be the focus of this year's Swiss Public Health Conference to be staged in Basel on 22 and 23 November 2017. In this interview, Nicole Probst-Hensch* outlines the opportunities and risks of personalised medicine. She discusses the right balance between the protection of personal data and access to such data, and she sets out her principles as a researcher.

Swiss TPH: **Personalised health is a hotly debated subject at present. Why is it attracting so much public attention?**

Nicole Probst-Hensch: Approaches based on personalised health and personalised medicine can produce favourable effects on people, but they also harbour certain risks. So we shall be asking a number of questions at the conference: how can we utilise the personalised medicine method to arrive at a better understanding of the causal risks of diseases? What benefits does this method offer in terms of epidemiological research, and which structures does it require? We shall also ask: is our medical profession prepared to carry out personalised therapies? And will these therapies be deployed promptly in hospitals outside of the urban centres too?

We shall go on to consider the cost aspect: personalised medicine does offer the promise of cheaper medications and lower healthcare costs thanks to its focus on each individual patient. But it would be equally easy to draw the opposite conclusion: medications tailored to the individual could push healthcare costs up. They could also deepen social inequalities, because not everyone is able to afford treatment of this sort – and two-class medicine is already a reality in low-income countries. Let's take new cancer medicines as an example. They are expensive because the development costs remain the same even if the medicine is only used for one sub-group of diseases. For this reason, cost-to-benefit analyses are needed in order to investigate whether these more costly medications really can be used more efficiently – and in cases where they are effective and have virtually no side-effects.

We are also interested in another question: how can personalised health methods and new technologies (such as drones) be deployed in practice to bring medicines to remote areas? Or, with reference to personalised nutrition: are we now able to adapt an individual's diet specifically to his or her metabolism and genetic profile?

To summarise: at the Swiss Health Conference 2017, we shall discuss aspects of personalised health ranging from research all the way through to application.

On the conference website, you write: 'Never before have we had access to more comprehensive data from such a large number of sources – and this opens up entirely new possibilities for the health sciences.' Big data: crucial for research, but also highly sensitive. As compared to other countries, where does Switzerland stand in this regard?

Speaking as an epidemiologist, and from the standpoint of Swiss TPH, we aim to provide data and evidence that will contribute towards preventing the occurrence of diseases because they are expensive to treat. This is especially true of chronic diseases which, as we know, are on the increase all over the world. We aim to encourage a healthy lifestyle, a healthy environment, social justice and

healthy workplaces. In other words, we want to contribute to healthy ageing. This means that primary prevention and (where appropriate) prevention through early detection are important concerns of ours. We lay the scientific foundations for this work with the help of long-term studies in this country and abroad. They provide the only basis that enables us to study biological processes in the body, various risks such as sitting for long periods or traffic noise, and the risks of developing diseases over longer periods, with a clear chronological sequence.

Could you explain that?

Long-term studies with biobanks or other detailed MRI data are an essential reference source for developing algorithms that enable early detection of diseases. What's more, long-term studies based on representative population samples enable us to collect data about how our healthcare system functions – especially if the participants also include individuals who have diseases or who become patients. If we obtain approval from them to use their medical data for research, we can also investigate questions such as: how is personalised medicine implemented and perceived in real life, and what are its consequences for the health of the population?

In the national long-term SAPALDIA cohort for the health of the Swiss population (financed for over 25 years by the Swiss National Science Foundation (SNSF)), we were able to show that about 50% of individuals with high blood pressure were unaware of their condition, and that monitoring for individuals with diagnosed high blood pressure could also be improved in 50% of cases.

The SAPALDIA study contains less data than similar studies in other countries.

Yes, that's been true until now. The UK biobank collects health data from 500,000 individuals and the figure for the German National Cohort (GNC) is 200,000. Studies on this scale – big data of this sort – are simply necessary for prospective recording of disease diagnoses, so that the complex interaction of many different risks can be investigated without impediments. The SAPALDIA study originally involved 10,000 individuals, and the figure is still 5,000 at present. This long-term data on the health of our country's population remains irreplaceable, and it's essential that the study participants can continue to be examined.

At the same time, Switzerland needs a major long-term study – including a biobank – to equip us for the future and to ensure that we remain competitive. I'm confident that this will come about. The Federal Office of Public Health (FOPH) is currently collaborating with epidemiologists at Swiss TPH in Basel and Lausanne, as well as the Swiss Biobank Platform, on a pilot study for a large national cohort that should meet the broadest possible requirements for health data in the future. So we are well on the way to ensuring the sustained development of the next generation of epidemiologists and public health specialists in our country – and they will be reliant on data of this sort.

As a scientist, how do you view the risk of abuse of health data?

This is an important question, of course, because the large volumes of health data collected in studies and by medical institutions are highly sensitive. As researchers, it is our responsibility and legal duty to use all the technologies at our disposal in order to prevent the abuse of data. But at the same time, we cannot allow ourselves to be hamstrung by the justified fear of abuse. We must also keep in mind what it would mean if we had no data: for without data, there can be no advances in research. Without data, the genomic knowledge that we have acquired at such great cost all over the world in recent years cannot be utilised to deliver direct medical benefits for people.

Health data is essential to monitor the quality and costs of our healthcare system. Without that data, we wouldn't even know how many people in Switzerland suffer from diabetes, depression or high blood pressure. The aim is to find the right balance between protection of data and access to data.

Interview: Anna Wegelin, Head of Communications, Swiss TPH. Basel, November 2017.

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Links:
Swiss Public Health Conference 2017: https://sph17.organizers-congress.org/

Epidemiology and Public Health at Swiss TPH: https://www.swisstph.ch/en/about/eph/

The SAPALDIA study: http://www.sapaldia.ch/de/