

## Digital Health – Part II: Social Aspects of Big Data

**Autor :** Reinhard Riedl

**Datum :** 13. Oktober 2016

**In this series of short papers recommendations for policy goals in digital health are outlined. These recommendations have been derived through the exchange of thoughts with scientists, experts on healthcare policy making, and strategy specialists. Recommendations in part II address social aspects of digital health.**

### **Recommendation II: We should focus on the SOCIAL ASPECTS OF BIG DATA**

We have become used to ignore social aspects in our highly individualized world. Speaking about personalized medicine seems to indicate that this is nothing social. But, personalized medicine, or precision medicine, as it's also called, relies on big data and thus it requires the health data of many. If we all provide our data, we all can potentially profit from a progress in medicine. If enough of us provide their data, others can profit without providing their data. If not enough provide their data, no one can benefit.

### **Multiple benefits at stake**

The benefits of big data in healthcare are manifold. It can be used in research. It can be used in carrying out prevention, diagnosis, therapy, care, and monitoring. It can be used for a remuneration relying on success rather than just on used resources. And it can be used in healthcare resource planning in politics. Thus the availability or non-availability of health data has a significant impact. Thereby useful data include bio-data, patient data, genomes, lifestyle data, and more.

Of course, it is possible to buy such data from countries where privacy is less well protected than in Switzerland or the European Union. Unfortunately this does not work equally well as using the data of the own population, because the distribution of genes and lifestyles has an impact on the distribution of diseases. So while in some cases using foreign data will work perfectly well, in other cases it won't work. However, there are many work arounds for missing data. Therefore, as long as the available data show enough genetic and lifestyle variety, one can usually profit without contributing our one's own data. So why give away our own data if we can buy those of others?

### **The solidarity issue investigated**

Well, to benefit from big data in healthcare without contributing to it also makes clear where the red lines of solidarity are defined. The comparison with seemingly related cases does not really hold. For example, if people live an unhealthy life, they may create financial risks for society, but their own risks is thereby much higher. On the contrary, if people do not provide their data, the risk that applying big data is not possible is shared by all. The key question therefore is, what people do risk if they provide their data in order to create public value to all. Do they risk anything at all?

Unfortunately they do. Privacy violations are possible. Social sharing of one's health data may be punished by crime. What is needed are therefore two things, a good governance implemented through good technology plus trust in technology and governance. Thereby terms have to be understood properly. Good governance is first and foremost measured by its impact, not by documents about it. It is thus impossible to separate organizational and technological issues of good governance. And trust is first and foremost measured by the contribution to the social creation of public value. Otherwise the way to no health data is paved with good intentions, good documents, and good speeches.

### **Actions to be taken**

In order to establish a living solidarity in health data sharing we need first to build secure platforms which limit possible violations in a use-case sensitive way. Second, we need to provide evidence about the security of the platform and the targeted use cases. Third we need to communicate that part of a lived solidarity in the healthcare system is the sharing health data.

Thereby a broad discussion of pros and cons will be necessary. We should not hide the fact, that big data has both the potential for reinsuring solidarity in the healthcare system and for destroying this solidarity. The latter will happen if individual insurance premiums are completely calculated from individual risks based on big data. So there is more than the risk of crime if people give away their health data and we better be transparent about all this. This does not alter the bottom line that the refusal to share health data prevents the application of big data for the benefit of all of us and therefore is a serious risk by itself. There is no solution, which is both safe and performs solidarity.