

„Die Bereitschaft zu Datenspenden ist sehr hoch“



Pandemien sind Krisenzeiten. Aber sie bringen auch eine erhöhte Solidarität mit sich. Die Medizinethikerin Alena Buyx setzt hier an und plädiert dafür, persönliche medizinische Daten in Form von „Datenspenden“ für die medizinische Forschung nutzbar zu machen. □

“There is a Great Willingness to Donate Data”

Infectious diseases and pandemics entail a whole string of ethical conflicts that are difficult to resolve. During such times of crisis, however, positive social effects can also be identified, such as increased solidarity and greater willingness to donate. Medical ethicist Prof. Alena Buyx advocates viewing medical data not only from the perspective of individual autonomy, but also making this data available for medical research in the form of “data donations”.

Prof. Buyx, infectious diseases and pandemics have been a major topic in recent months. What ethical questions do you see arising in this context?

Pandemics involve a deep ethical conflict – something we have pointed out in the German Ethics Council. On the one hand, we need to ensure that our healthcare system remains able to function. It is therefore necessary to put measures in place to contain the spread of the pandemic. On the other hand, the knock-on effects of these lock-down measures include dramatic economic, social and psychological damage. There are, as it were, two sides to this coin. We have to find some way to balance the two aspects.

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Can medical ethicists propose solutions or issue recommendations in the face of such conflicts?

It is not usually possible to resolve this conflict; however, we can attempt to attenuate its effects and preserve proportionality. We must therefore continuously examine whether the measures currently in place to contain the pandemic are still proportionate. This involves answering questions such as: has the evidence changed? Have we learned anything new – either about the virus or about whether and to what extent the measures in place are succeeding, etc.?





“We have a shared interest in protecting the health of everyone.”

Alena Buyx

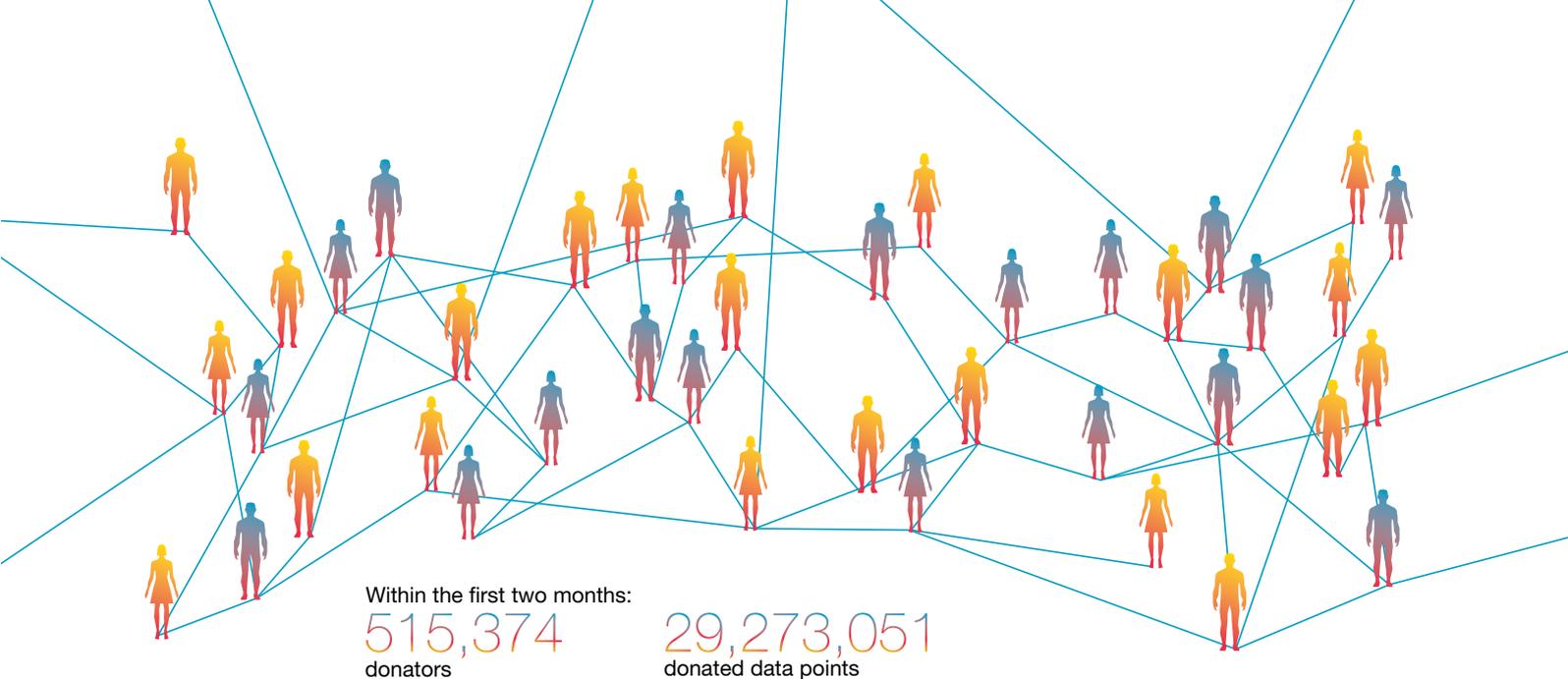
So, we should not simply leave these determinations in the hands of medical experts?

The Ethics Council has said that we should not adopt an approach in which we proceed exclusively or automatically on the basis of data presented by virologists and epidemiologists – and regard everything else as secondary. That is not acceptable. We need to make political decisions that cannot be dictated solely by data about the pandemic. Numerous other aspects and interests need to be taken into account, and balanced.

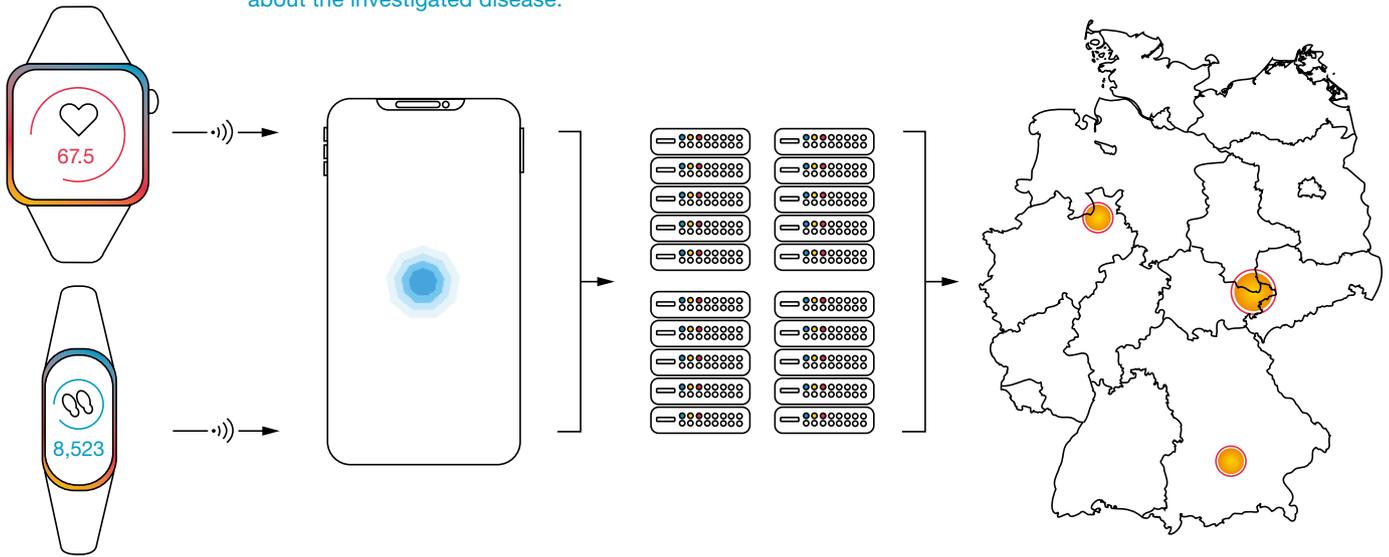
In the context of a crisis, people show more solidarity. Is this a topic that has played an important role for the Ethics Council and has been raised in discussions?

In the past, data protection legislation and regulations ensured that medical information was disclosed in a

manner that was very much geared towards minimizing the risks. The instrument of informed consent was intended to ensure this, and to enable data autonomy. In 2013, my colleague Barbara Prainsack and I published a paper in an international medical law journal that has been frequently cited in which we indicated that consent is about more than just autonomy and risk minimization. When people participate in research projects involving huge volumes of data, they also have a prosocial motivation for doing so. By this, we mean that people would like to do something voluntarily for others who might have a similar illness, even if doing so exposes them to minor risks, such as in terms of data protection. You might say that we have a shared interest in protecting the health of everyone. We should therefore also regard this form of research as solidarity in practice. ▶



Data donations like the Corona Data Donations app from the Robert Koch Institute are often about collecting as much data as possible from as many participants as possible. The more data, the better it can be searched for patterns that help answer questions about the investigated disease.



Fitness bands and smartwatches collect data like activity and heart rate.

Users have entered data like rough age, weight, height as well as their zip code into the app.

A central server processes the data.

Changes in the regional distribution of parameters like heart rate and change in body temperature are visible. Such data can help identify the onset of an infectious outbreak.

What is data donation?

For patients, donating data means making their medical data available for research purposes, usually in anonymized form. This data might relate to relatively neutral information such as their sex or weight, or data taken from fitness apps; however, it could also contain sensitive information such as X-ray images or the results of laboratory tests. Scientists can use the information gathered in this way to gain new insights and derive new therapies.

One current example is the German Corona Data Donations app developed by the Robert Koch Institute. The RKI has appealed for users to provide data from fitness trackers and smartwatches, as it is hoped that such data will provide indications of symptoms of a COVID-19 infection. The scientists hope to learn more about the virus' propagation as well as about the number of unreported infections. The information will help to derive better measures against the virus.

Graphics: edlundsepp (source: corona-datenspende.de/science); Picture credit: Juli Eberle

“Data donation can be structured so that it does not conflict with data protection provisions in any way.”

Alena Buyx

And voluntary data donation is one form of solidarity in practice?

The idea of donating data is now also being addressed as part of wider public discourse. To give some background on this: We performed several studies on the secondary use of data in clinical settings. Secondary use means that data that was primarily generated for a different purpose is used for other research questions. In our study, we identified that many people seek to act in a prosocial and solidary manner and are happy to donate their data – even if the precise research question this might help to address is not yet clear when the data is collected. That was the case for well over 80 percent of respondents, sometimes over 90 percent. We can therefore assume that a lot of people are highly socially motivated to donate their medical data. We also learned, however, that people only wish to do so when their donation serves the common good – in this case, publicly funded medical research. They would not be prepared to donate their data to companies such as Google or Facebook. Data donation must therefore be a truly solidary practice.

How exactly is donated data protected?

Obviously, donated data needs to be secured and protected. Donating data does not mean waiving all forms of data autonomy or data protection. Requirements regarding data protection still need to be observed. People expect there to be protective measures in place, such as anonymization, encryption, secure servers and access restrictions. This should not be a problem: Data donation can be structured so that it does not conflict with data protection provisions in any way. In such circumstances, people are very willing to donate their data and even their biomaterials to research for a purpose that serves the common good.

Do you think it would be sensible to make such forms of data donation mandatory, perhaps in the form of legislation?

I am always a fan of voluntary solutions where possible. In my opinion, mandatory data donation would be an absolute last resort – and in any case, I do not think we need to make it obligatory. If you explain what exactly you need the data for, there will be significant willingness to donate – simply because we are so willing to act in solidarity with others.

We should focus much more on this solidary motivation. Unfortunately, it has not yet been incorporated in our data protection regulations. I would advocate creating more opportunities for people to donate more of their data.

■

Klaus Manhart



Prof. Alena Buyx

Alena Buyx is Professor of Ethics of Medicine and Health Technologies and Director of the Institute of History and Ethics of Medicine at TUM. Professor Buyx is a doctor and holds degrees in philosophy and sociology. Her research covers the full breadth of ethics and biomedicine and public health, with a particular focus on the ethics

of medical innovations and health technologies, research ethics, issues of solidarity and new participatory approaches in biomedicine. She is chair of the German Ethics Council and member of the WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing in 2019.
