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## **Your health – your data Health data is transforming the EU**

### **Final report on the dialogue on the future of the EU on 10 July 2021 in the context of the Conference on the Future of Europe**

#### **Dialogue on the Future of the EU at the Federal Ministry of Health**

Our lives and healthcare systems are becoming ever more digital. In a digitalised and innovative EU, how should healthcare be organised in future? How can not only we, but also the entire population of the EU, benefit from our personal health data, while simultaneously ensuring the data is adequately protected?

In a virtual dialogue, twelve citizens debated and developed concrete ideas on the future handling of health data in the EU and discussed their views on the topic with Federal Minister of Health Jens Spahn. The debate was moderated by Sebastian Tittelbach, with Prof. Eva Winkler (University of Heidelberg, oncologist, specialised in the areas of research ethics and doctor-patient relationship) and Birgit Bauer (Digital Health & Social Media Expert and Patient Expert) lending their expertise.

#### **Participants**

Participants were selected in an application procedure and were intended to provide as representative a sample as possible of the overall population. An emphasis was placed on equally representing both genders in the selection process. In addition, the age groups represented ranged from a 14-year-old adolescent to the generation 50+ and participants included pupils, students and professionals from various different fields of work.



Photo: Frederic Schweizer

**The demands developed by the citizens participating in the dialogue cover three topics:**

## I. Enormous opportunity: Cross-border exchange of health data

In the future, we would like to see fast, simple, impartial, trustworthy, secure, accessible and easy-to-use exchange of health data within the European Union.

Therefore, the European health ministers and the healthcare industry should create the legal framework necessary to achieve this goal.

Otherwise, we fear that patients could be harmed, since the possibilities of using health data to support their treatment will not be taken full advantage of, and that the inefficiency of our healthcare system will increase.

Our concrete proposal is to create a standard for cross-border data processing that ensures interoperability.

We believe that this will facilitate better communication between public health stakeholders, lead to improvements in the research and treatment of rare diseases, increase economic efficiency, facilitate the detection of therapy-related risks and accelerate research and diagnostics. This will also contribute to promoting the European idea.



Graphic Recording: Anne Lehmann/Photo: Frederic Schweizer

## II. Secure handling of health data is key for a successful European Health Data Space

In the future, we would like to see that everyone will maintain control over their own data. We do not perceive data protection as an obstacle. We want to prevent commercial use by third parties for advertisement and marketing purposes, but enable research that is underpinned by health data. Information on specific health data should be brought to the public's attention on fixed dates to facilitate progress in the respective areas.

The EU should rely on open source software for its Health Data Space. It must be made clear that data storage will be transparent and data will be stored in a clearly designated location. There may not be any disadvantages for people who decide not to make their data available. An opt-out solution is required, and citizens need to have the possibility to 'hide' individual pieces of their data.

Otherwise, we would risk a loss of acceptance of the storage of data. We also see a risk of potential cyberattacks.

Our concrete proposal is that the development of the necessary software should be monitored by the Government and that every citizen should be able to manage their data themselves at any time.

We believe that this will increase citizens' trust in the European Health Data Space, bring to light its benefits and enable everyone to understand what effects the sharing of individual data will or might have.



Graphic Recording: Anne Lehmann/Photo: Frederic Schweizer

### III. The success of the European Health Data Space begins in schools

In the future, we would like to see that starting at school, already different population groups are informed and educated about the European Health Data Space on an ongoing basis in order to also awaken the interest of groups such as senior citizens or the less digitally savvy in this topic.

We call on the health ministers of the EU to promote the project through high-profile campaigns, just as they did in the context of the vaccination campaign. Health education and the topic of data protection should become part of school curricula.

Our concrete proposal is to find more advocates for this project and to equip patient organisations with a budget that will allow them to raise awareness regarding the topic. We advocate for it to be made obligatory for everyone to decide whether they want to share their data. Problems and opportunities must be communicated in a clear manner.

People should be informed about the Health Data Space long before a need for medical treatment arises or an emergency occurs.

We advocate introducing an incentive system for all those who contribute to the European Health Data Space by sharing their data.



Graphic Recording: Anne Lehmann/Photo: Frederic Schweizer



## **Conclusion**

In a committed, objective and respectful debate, both during the workshop and the discussion with Federal Minister of Health Spahn, many important aspects concerning the future handling of health data within the EU were addressed.

In a survey conducted in advance on the participants' personal view regarding the question 'What do I think about my health data being processed in all European states? In my opinion, do the risks outweigh the benefits (0) or are the benefits greater than the risks (10)?', the mean score was 7.3.

By the end of the event, this view had changed to a mean score of 8.3. During the event, the benefits of and the need for a pan-European use of health data were discussed and identified in a joint dialogue.

All participants are aware that it will not be possible to implement all of the demands developed in the context of this event and that the implementation of some of these demands will take a longer period of time. However, the European Health Data Space is perceived to be a forward-looking task and should therefore continue to be a priority topic.

Berlin, 10 July 2021