

PRESS RELEASE 03/2023

## Ethics Council: Making better use of health data without weakening data privacy

Berlin, 21 March 2023

On 22 March 2023, the German Ethics Council convenes a public evening event as part of the Bioethics Forum series on the topic of “Patient-Oriented Data Use”. The event aims to facilitate a constructive dialogue on how health data can be made more easily usable for healthcare, personalisation of treatments, and research, while respecting data privacy.

Health data is still used far too little for research, although this would be legally permissible and considerations of patient welfare would even require it. The German Ethics Council seeks to identify the main issues at stake and to find solutions. To this end, it invites experts from the fields of data privacy, politics, ethics, law and technology to discuss concrete examples and improvements for the future.

Alena Buyx, Chair of the German Ethics Council, says: “If only it can be harnessed, health data holds enormous potential for patient welfare. To make this possible, we don’t need less data privacy, we need to implement it better.”

At the beginning of the event, physician Tobias B. Huber and patient representative Patrick Schloss will report on the challenges they face with data privacy in practice: For example, it is difficult to establish contact between self-help groups and patients in a way that complies with data privacy rules. Another problem: Consent forms for data use are so long that most patients sign them or decline consent without reading them.

The examples are then contextualised: from a legal perspective by Anne Riechert (Frankfurt University of Applied Sciences), from a technical and organisational point of view by Sylvia Thun (Charité – Universitätsmedizin Berlin) and from an ethical perspective by Dirk Lanzerath (German Reference Centre for Ethics in the Life Sciences). Finally, possible solutions are discussed. Tobias B. Huber and Patrick Schloss will participate in the final discussion alongside Ulrich Kelber, the Federal Commissioner for Data Protection and Freedom of Information, and Susanne Ozegowski, Head of Department for Digital Affairs at the German Federal Ministry of Health.

In its Opinion “Big Data and Health – Data Sovereignty as the Shaping of Informational Freedom” published in 2017, the German Ethics Council already provided fundamental considerations on this topic.

Volker Lipp, Vice-Chair of the German Ethics Council, emphasises: “The use of health data is subject to strict conditions because such data contains highly sensitive information that needs protection. At the same time, its use for medical research and care is of great importance.”

### Members

Prof. Dr. med. Alena Buyx (Chair)  
 Prof. Dr. iur. Dr. h. c. Volker Lipp (Vice-Chair)  
 Prof. Dr. phil. Dr. h. c. Julian Nida-Rümelin (Vice-Chair)  
 Prof. Dr. rer. nat. Susanne Schreiber (Vice-Chair)

Prof. Dr. iur. Steffen Augsberg  
 Regional bishop Dr. phil. Petra Bahr  
 Prof. Dr. theol. Franz-Josef Bormann  
 Prof. Dr. rer. nat. Hans-Ulrich Demuth  
 Prof. Dr. iur. Helmut Frister  
 Prof. Dr. theol. Elisabeth Gräß-Schmidt  
 Prof. Dr. rer. nat. Dr. phil. Sigrid Graumann  
 Prof. Dr. rer. nat. Armin Grunwald  
 Prof. Dr. med. Wolfram Henn  
 Prof. Dr. rer. nat. Ursula Klingmüller  
 Stephan Kruijff  
 Prof. Dr. theol. Andreas Lob-Hüdepohl  
 Prof. Dr. phil. habil. Annette Riedel  
 Prof. Dr. iur. Stephan Rixen  
 Prof. Dr. iur. Dr. phil. Frauke Rostalski  
 Prof. Dr. theol. Kerstin Schlögl-Flierl  
 Dr. med. Josef Schuster  
 Prof. Dr. phil. Mark Schweda  
 Prof. Dr. phil. Judith Simon  
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Ursula Klingmüller, member of the German Ethics Council, adds: “Better use of data benefits everyone and is also approved of by the vast majority of patients. Unfortunately, data privacy is often handled too restrictively in research due to uncertainties about its handling.”

The event takes place from 6:00 pm to 8:30 pm at the Berlin-Brandenburg Academy of Sciences and Humanities (Leibniz-Saal). The event will be held in German. For on-site participation, registration is required: <https://www.ethikrat.org/forum-bioethik/anmeldung>. The event will be broadcast online at <https://www.ethikrat.org/live>. No registration is required to follow the event online. The audience is invited to join the discussion using the hashtag #Datennutzung.

For the hearing impaired, there will be subtitling on-site and online. Following the event, a video recording and a transcript will be made available on the website of the German Ethics Council.