

## Survey „data donation“ for medical research

- ▶ Implemented by forsa Politik- und Sozialforschung GmbH
- ▶ On behalf of the TMF e.V.
- ▶ Representative online survey panel forsa.omninet
- ▶ 1.006 respondents aged 18 and over in Germany
- ▶ Survey period 13 to 18 August 2019
- ▶ Scientific advice: Gesine Richter, M.A., MBA, Prof. Dr. Michael Krawczak

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## Survey „data donation“ for medical research

Assuming that in the future your personal health data, such as your medical history, examination results, X-ray images, etc. can be stored online in a digital health record. Would you agree that your personal health data is used anonymously and free of charge for the purpose of medical research so that in the future diseases can be better recognised and new treatments developed?

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## Consent to data donation for medical research



**79%**  
agree

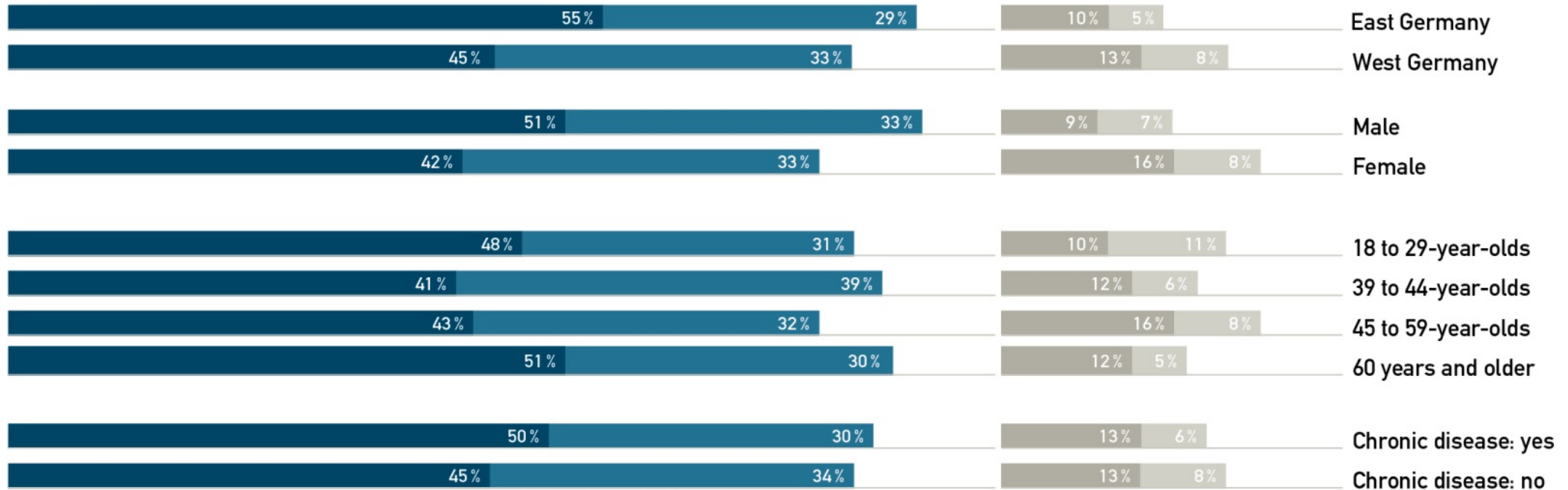
Source: TMF e.V. 2019 | Data base: 1006 respondents aged 18 and older in Germany

# Consent to data donation for medical research



fully agree | agree

disagree | strongly disagree



Source: TMF e.V. 2019 | Data base: 1006 respondents aged 18 and older in Germany

## IF DISAGREED/STRONGLY DISAGREED

Why *wouldn't* you agree that your personal health information is used for medical research? What reasons do you have to disagree?

The following reasons speak against donating data:	Total **) %
Concerns regarding non-compliance with data protection regulations and/or misuse of data	60
Right to one's own data, personal right	20
Lack of benefit for research	13

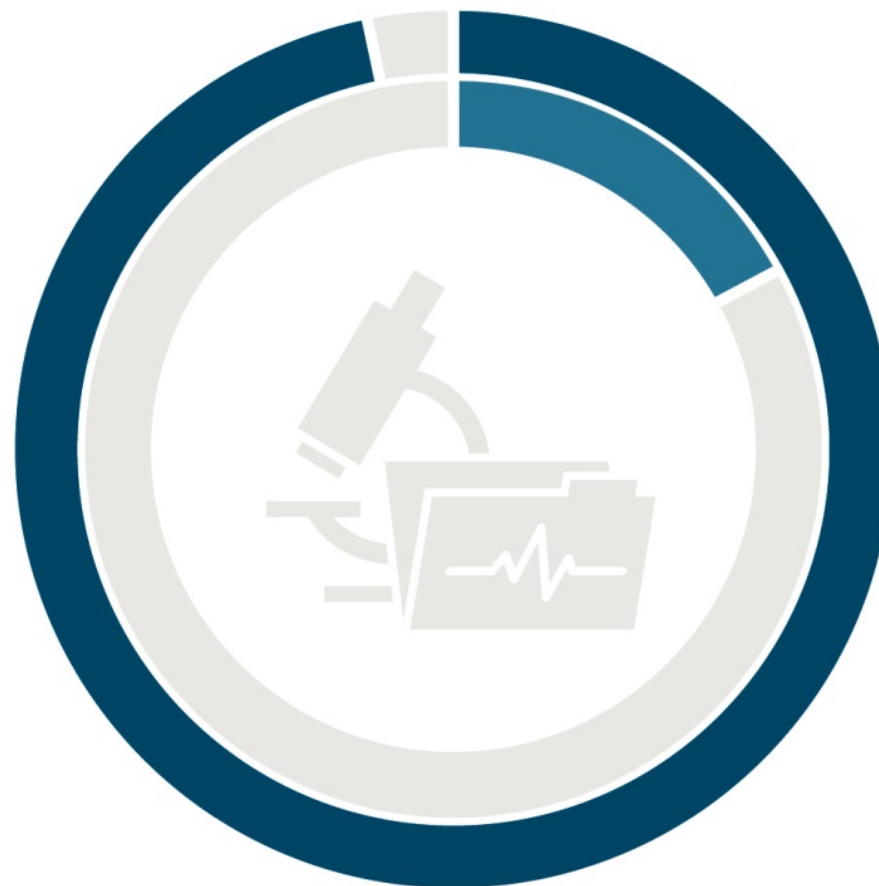
\*) Basis: 204 respondents who disagree/strongly disagree that their personal health data is used for medical research

\*\*) open question, multiple answers possible

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## With whom would the Germans share their health data?

- 97% Scientists at universities and public research institutions
- 17% Scientists from industry and private companies

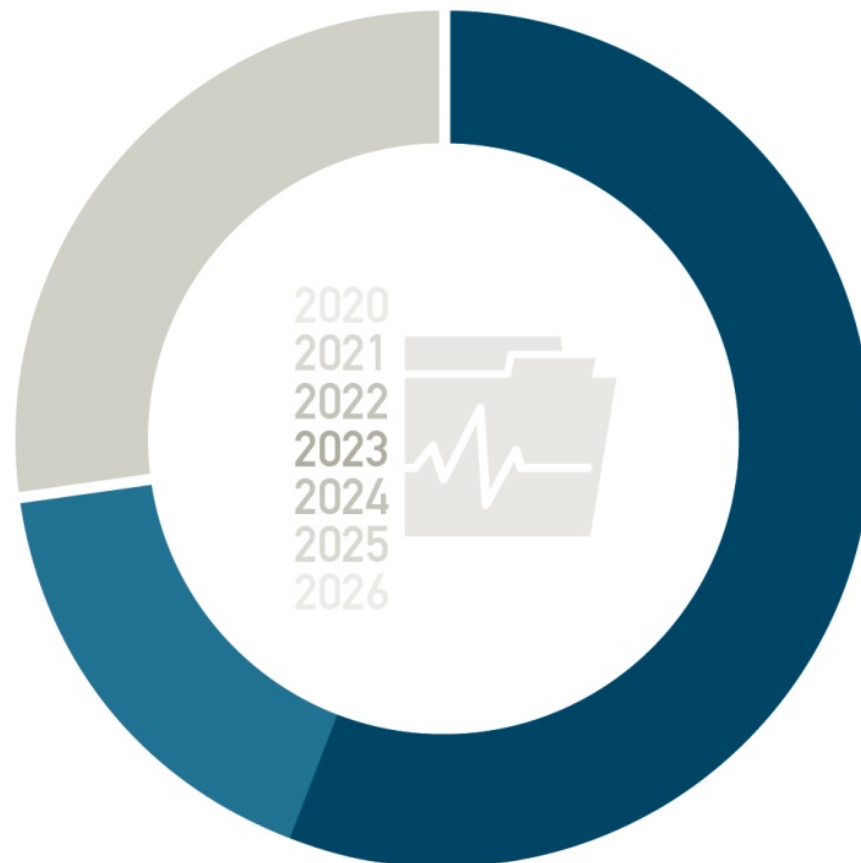


**97%**  
support public research

Source: TMF e.V. 2019 | Data base: 793 respondents who would agree to their personal health data being made available for medical research

## How long should the health data be used after data donation?

- 56% unlimited data use
- 17% for the next five years
- 27% ask for consent for each research project



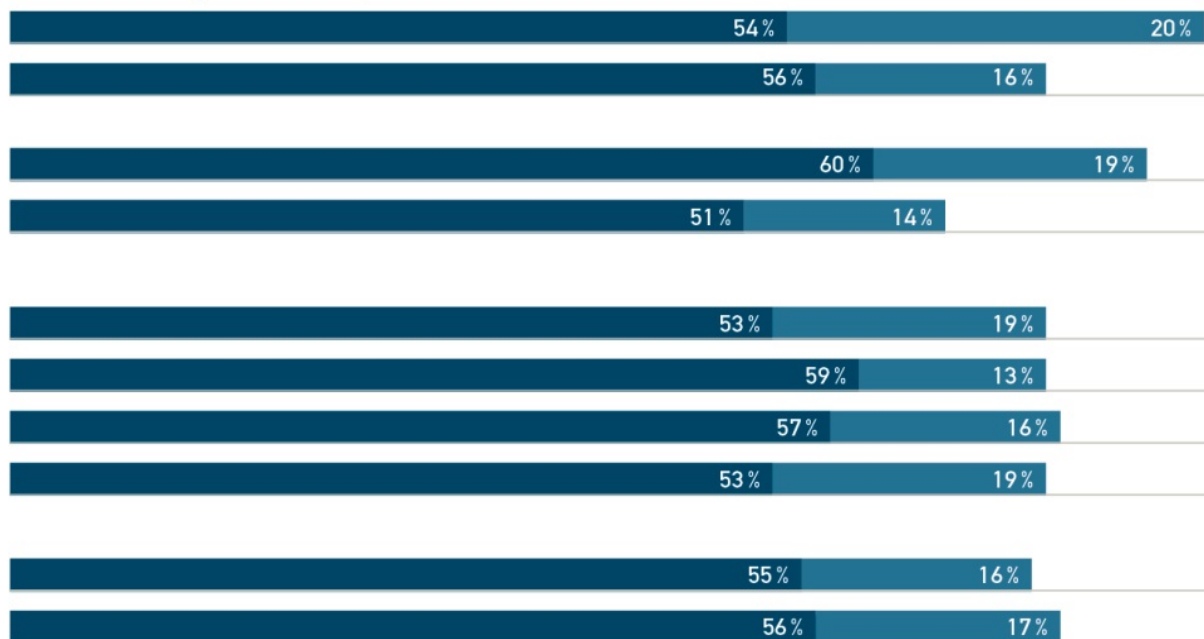
# 73%

agree to long-term data use  
(unlimited and for the next five years)

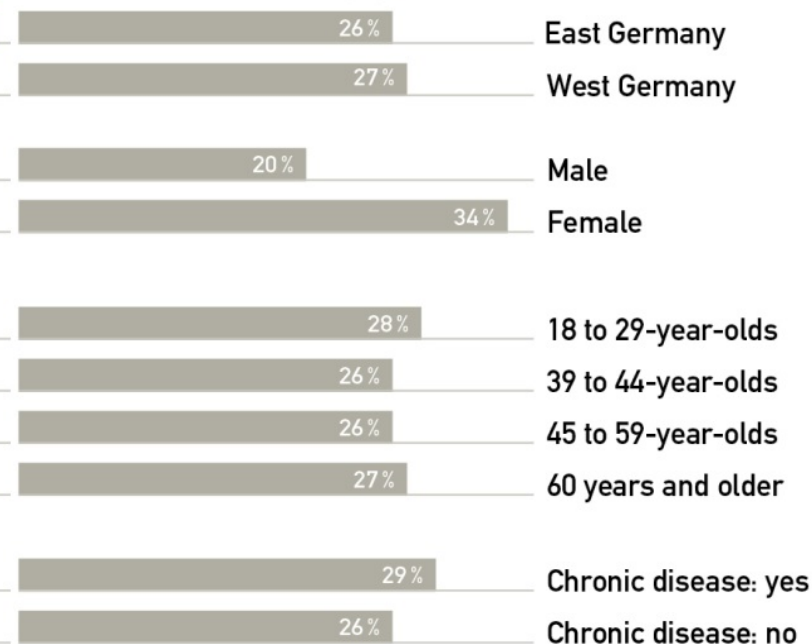
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## How long should the health data be used after data donation?

Unlimited data use | for the next five years



ask for consent for each research project



Source: TMF e.V. 2019 | Data base: 793 respondents who would agree to their personal health data being made available for medical research



Further information is available at [www.tmf-ev.de](http://www.tmf-ev.de)

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