

# Secondary research use of personal medical data: Patient attitudes towards data donation (=automatic data release without explicit consent)

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## Why the discussion about "data donation" in Germany (=legal permission for automatic data release without explicit consent unless actively denied by data subject)?

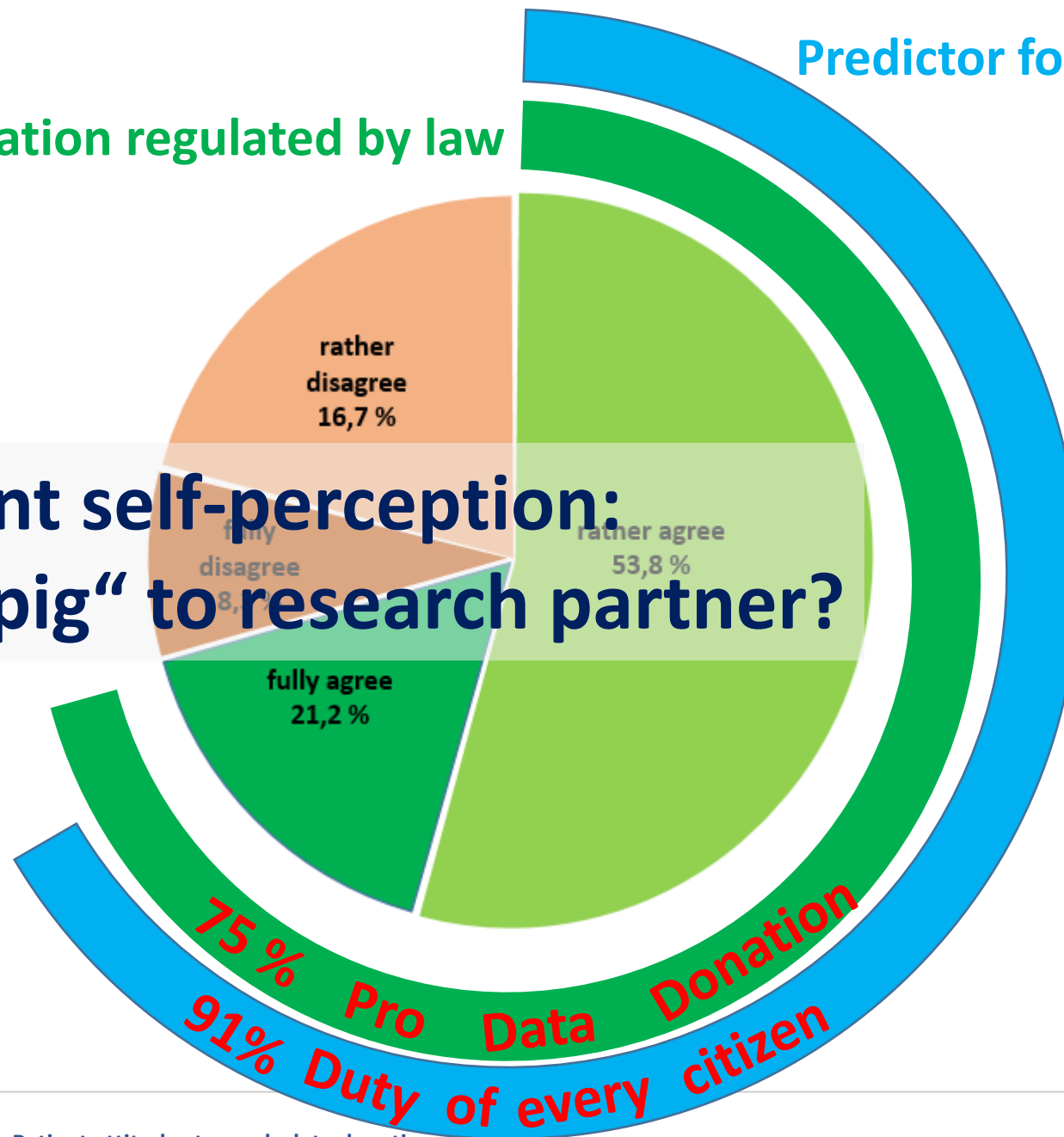
- Growing desire of patients and population to actively contribute to research
- Use of data from different contexts for research purposes
- Lack of representativeness due to low and distorting consent rates – consent bias
- Therapeutic and diagnostic misunderstandings
- Lack of understanding
- Equity problems: exclusion of certain groups from research
- GDPR – Art. 9 Section 2 (j) allows processing of personal data if  
“necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes”

## Broad Consent and no-consent policy: Studies assessing acceptance and motivation

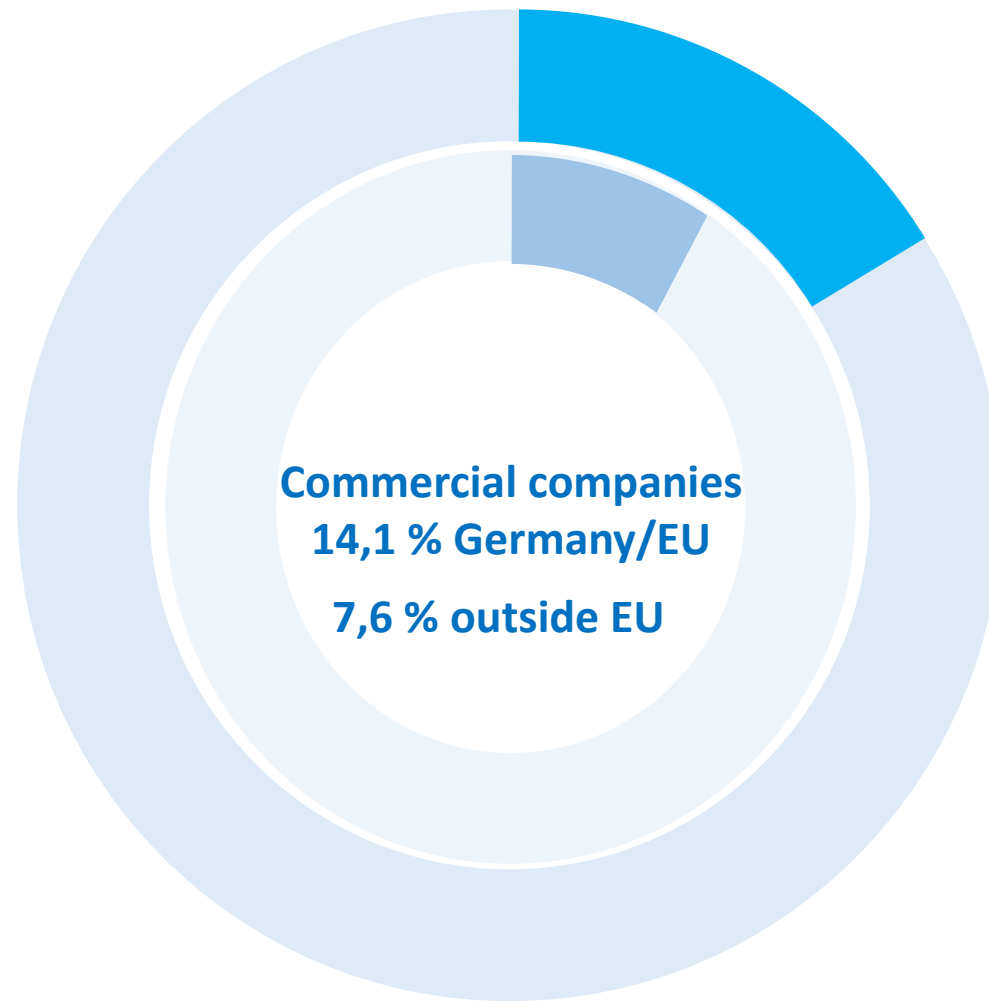
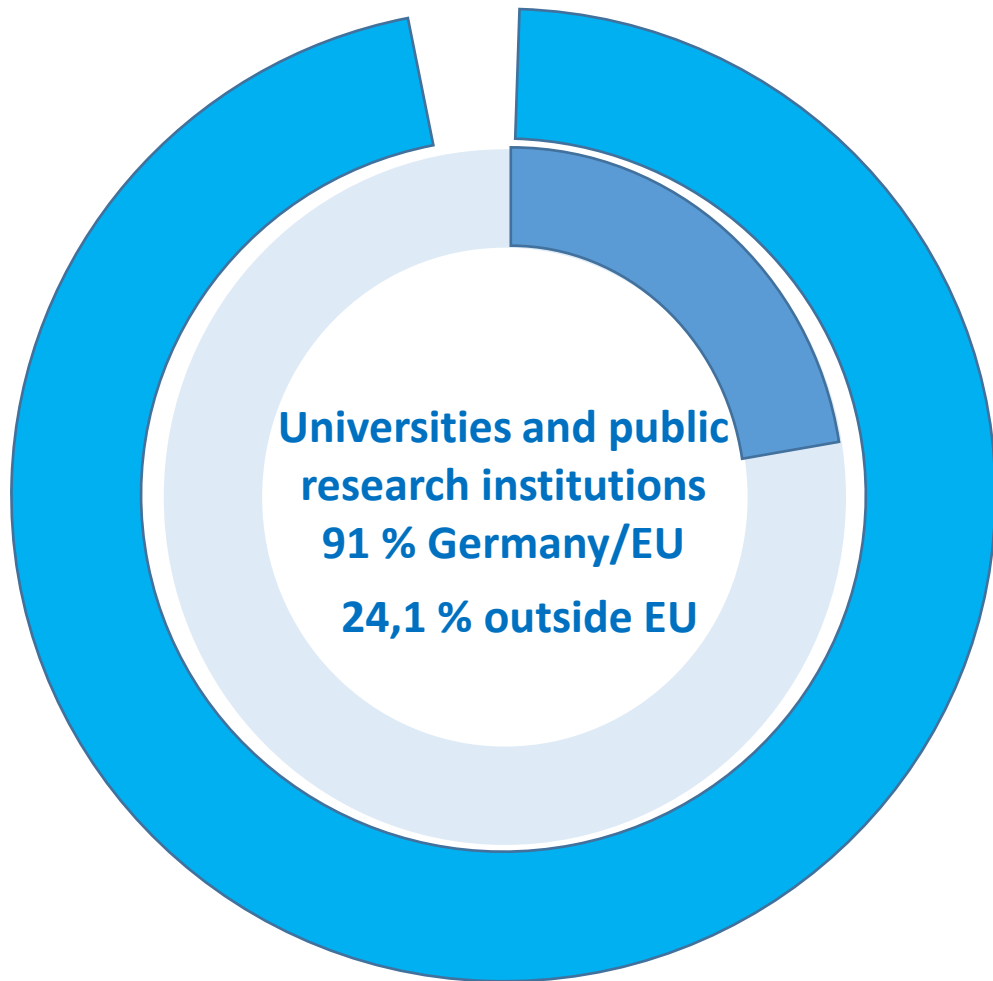
	Study 1	Study 2	Study 3
<b>Who</b>	Patients at the Comprehensive Center for Inflammation Medicine (CCIM) and in 2020 also at the Center of Internal Medicine/General Surgery (IMAC) UKSH, Campus Kiel		
<b>When</b>	2015/2016	03/2018	05/2020 and 11/2020
<b>Reason</b>	One of the first hospital-wide broad consents in Germany	GDPR: leeway whether consent is required for secondary data use in medical research	Initiatives work on infrastructures for data-interoperability
<b>Aim</b>	<b>87% acceptance of broad consent</b>	<b>93% acceptance of broad consent</b>	<b>Attitude towards data-donation as opt-out</b>
<b>How</b>	<b>Motivation: altruism, solidarity, reciprocity, gratitude</b>	<b>76 % approval of abolishing consent</b>	500/150 delivered 377 (75,4%)/ 132 (88%) compl.
	Richter G et al., Genetics in Medicine 2018.	Richter G et al. Europ. Journal of Human Genetics 2019.	Richter G et al. BMC Med Ethics, 2021.

Acceptance of data-donation regulated by law

Changed patient self-perception:  
From „guinea-pig“ to research partner?



# Data usage: Who should be allowed use of data donated for medical research?

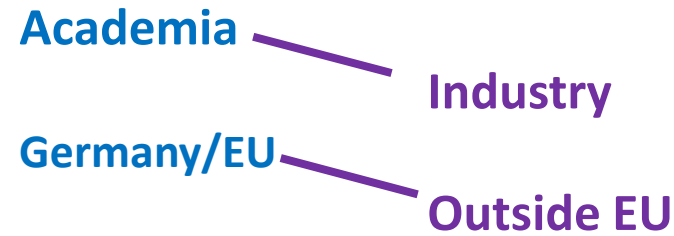


## Conclusion and next steps

**Awareness of cooperation** between academic and commercial research

**Acknowledgment of the importance** of commercial research

## Slope of trust



**Reservations** against commercial data usage:

- insufficient data protection
- rejection of profit-making

**Majority accepting data-donation as opt-out**

**Evaluation** of findings within a broad population-based survey

## Counteractions

- demand for a **legal regulation**
- stipulating that **data are not sold**
- **control** of data use
- and data protection by **independent bodies**

- ? **Change in Patient-self-conception:**
- ? **duty to contribute to research**
- ? **How to reach sufficient literacy to enable informed self-determined decision-making**

Thank you for your attention.

Please contact me  
for further questions or  
if you are interested in our  
current nationwide survey:

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