

### Motivation:

- A vast amount of data is available but remains **untapped**, especially in the healthcare sector, due to stringent data protection laws.
- Improve patient care and drive innovation** by developing a new **anonymisation** approach using available data.
- Key goal:** shift the focus from data **ownership** to data **utilization**
- Proposing that the value lies in how **data** is **used** rather than who **owns** it.
- Treating data as a **common good**, accessible **to all sectors** of society

### Aim:

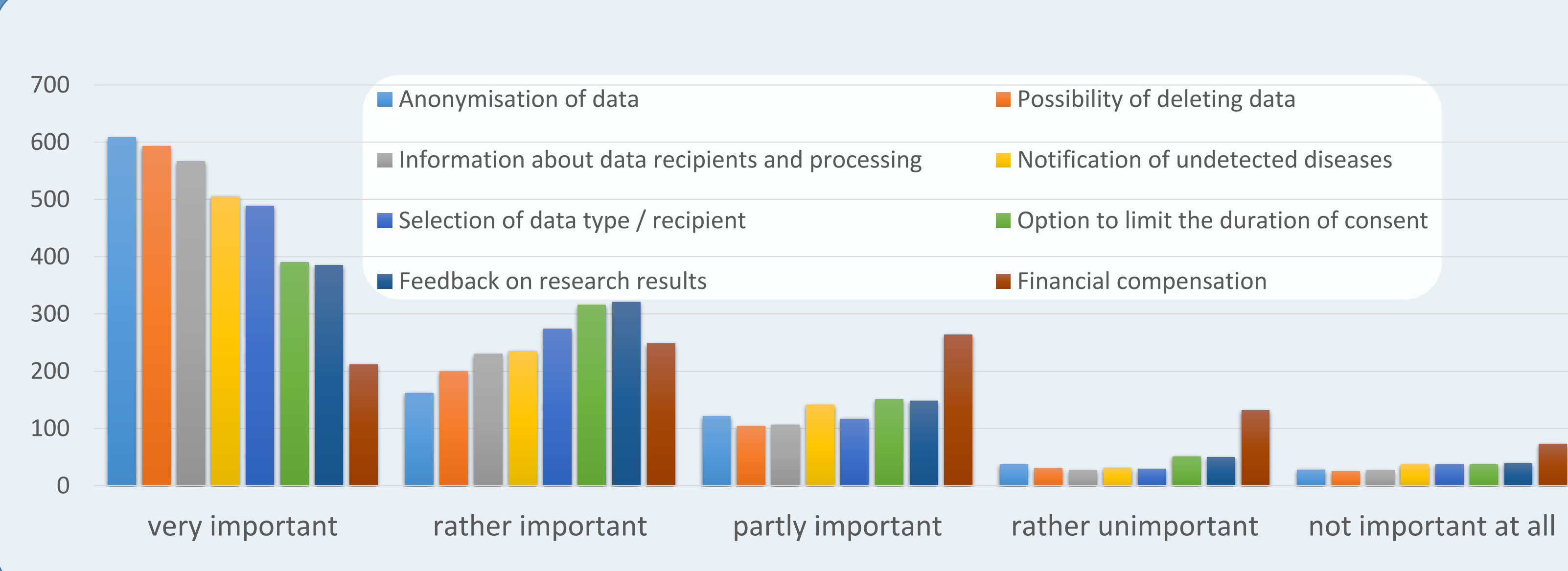
- Innovation** in the **anonymisation** of personal **health data** through the AVATAR project.
- Creating **digital avatars** from a **decentralised** data pool
  - (based on real data and preserving anonymity.)
- Opening up new **possibilities** for using **existing data** in practice, without data protection risks.
- Adapting the consent process for data donations to **specific utilisation requests** enables the use of routine care data in **research and development**.

### Incentives for sharing health data

<b>Transparency<sup>1</sup></b>	Purpose	Authorised users	Results
	Notification	Audit log capability	Data management
<b>Individual control<sup>2</sup></b>	Granularity (data type)	Authorised users	Purpose
	Consent	User-friendliness	Interaction tool
	Deletion of the data	Self-protection measures	Time for consideration
	Data type	Limited in time	Stop access
Restriction/blocking of specific information			
<b>Trust</b>	Trust in data protection	Trust in providers and organisations (data recipients)	Guidelines for organising and sharing data
	In patient organisations / In doctors	Perceived trustworthiness (in people, companies, government)	Ignorance of dangers
<b>Altruistic motives</b>	<b>Severity of the disease</b>	<b>Participatory research</b>	<b>Demographics</b>

### Obstacles of sharing health data

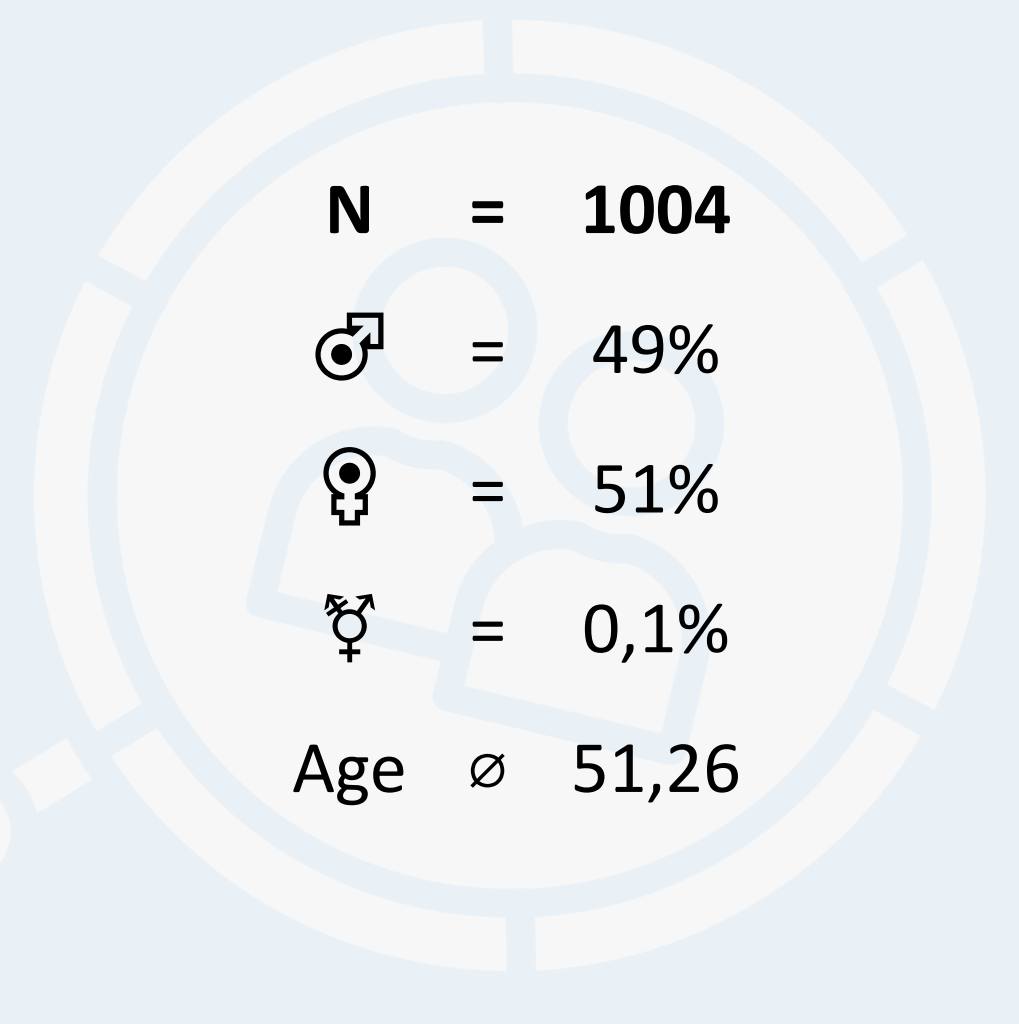
<b>Lack of control</b>	Unauthorised disclosure	Data cannot be withdrawn	Lack of control due to illness
	Ignorance about use of data		
<b>Distrust in data protection</b>	Abuse of data	Centralised storage	Automatic storage
	Unauthorised access	Fraud	Identity theft
	Publication online	Distrust in health insurance companies	Distrust in research from pharmaceutical companies
<b>Secondary transfer</b>	Non-ethical use of data	Abuse by government	Commercial use
	Unknown applicant		
<b>Access and data control<sup>3</sup></b>	Lack of choices in release decision	Lack of personal control	Lack of mechanisms for granular control
	<b>Insecure handling of data</b>	<b>Absence of feedback</b>	<b>Concerns about privacy</b>



### Phone survey: Willingness and acceptance of data donation (11.2023-12.2023)

#### Topics covered by the questionnaire:

- Digital competence
- Willingness to share personal health data
- General attitudes towards data donation
- Motivation to donate data
- Trust in institutions and data protection/privacy
- Willingness to donate



Available Data Source

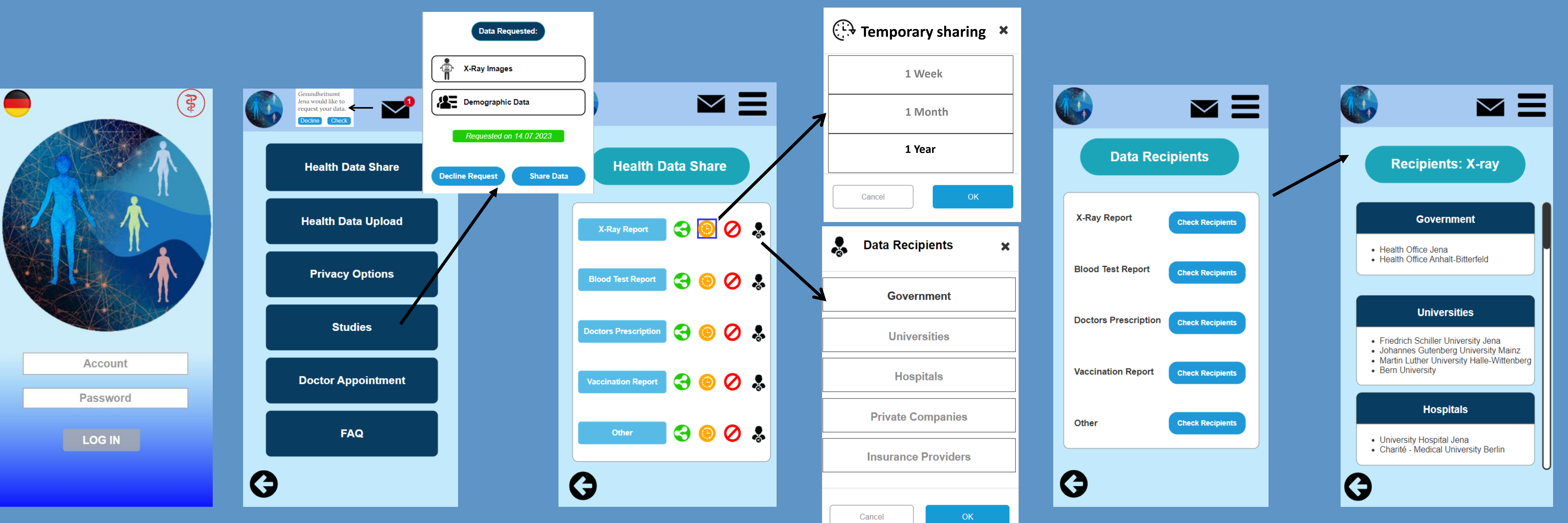
Start of Data Request (Data Recipient)

Receiving Data Request (Data Donor)

Performing Data Exchange

Dispatch

Deletion of all internal data relating to the request



### References

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2) Sankar, P., Mora, S., Merz, J. F., & Jones, N. L. (2003). Patient perspectives of medical confidentiality: a review of the literature. *Journal of general internal medicine*, 18(8), 659-669.  
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3) Moon, L. A. (2017). Factors influencing health data sharing preferences of consumers: A critical review. *Health policy and technology*, 6(2), 169-187.