AVATAR-TRANSFER · DLR

Self-determined sharing of health data

Dynamic Consent as a socio-technical design problem: balancing user sovereignty, practicability and data utility

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1 Motivation & research question

Control vs. practicability

Meaningful control over health data must not turn into consent fatigue. [1] [2]

Sovereignty vs. data utility

Data providers need to protect their data; data users need complete, high-quality data. [3]

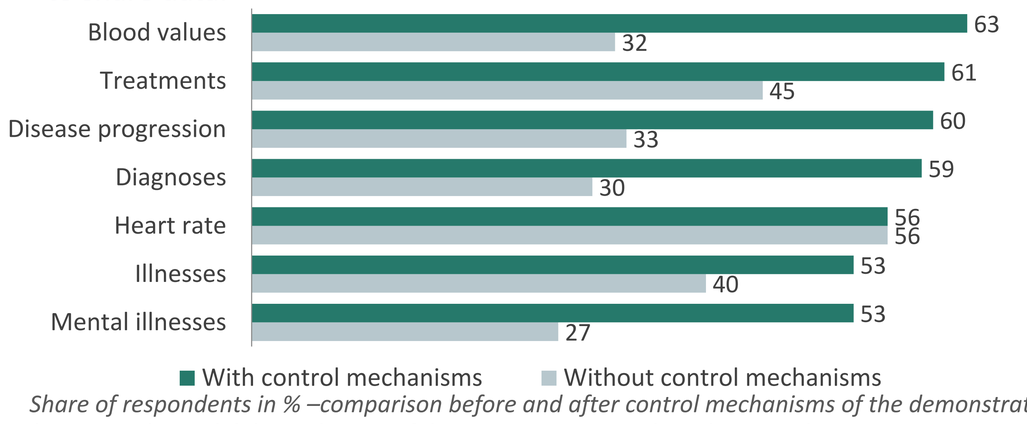
Data re-use vs. sovereignty

Broad consent can reduce purpose specificity and transparency (GDPR requirements), while narrow consent can constrain future data reuse. [1] [6]

Research question:
How can Dynamic Consent balance user sovereignty, practicability and data utility?

Empirical starting point from AVATAR

Willingness to share health data is strongly influenced by transparency and perceived control. Results from an interactive workshop presenting the AVATAR platform demonstrator indicate that providing users with transparent information and granular control over their health data can positively affect their willingness to share data.



Share of respondents in % –comparison before and after control mechanisms of the demonstrator (Temporarily availability, selection of data recipients, granular release etc.)

2 Dynamic Consent research approach

Requirements of data providers [3] [4]
control granularity · transparency · delegation · security preferences

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Requirements of data users
data quality · completeness · information needs · practicability

↓

Compatibility matrix
compatible needs · trade-offs · conflicts

↓

Modular Design Toolkit for dynamic consent [2]
information · control · delegation · incentives · UX patterns

↓

Design Toolkit & evaluation [6]
prototype tested in secondary-use scenarios

3 Compatibility matrix

The central instrument: provider sovereignty needs are set against data-user requirements to expose where Dynamic Consent options are compatible, where they force trade-offs, and where they conflict. [6]

Provider need \ User requirement	Data quality	Info flow	Reuse flexibility	Responsible use	Security
Granular control	●	●	●	●	●
Transparency	●	●	●	●	●
Delegation	●	●	●	●	●
Withdrawal / flexibility	●	●	●	●	●
Security expectations	●	●	●	●	●

● compatible ● trade-off ● conflict

Illustrative structure — cells will be populated empirically from data-donor surveys and data-recipient interviews.

4 Socio-technical bridge

Empirical evidence
Surveys and interviews with providers and users

→

Design decisions
compatibility matrix and toolkit of consent options

Trustworthy secondary use = user sovereignty + usable data + feasible dynamic consent solution

Consent is treated as a design object, not a legal formality: empirical requirements shape the architecture, and the architecture feeds back into what can realistically be offered to data providers. [5]

5 Expected scientific outcomes & transfer

Empirical requirements model of Dynamic Consent from both provider and user perspectives

Populated compatibility matrix as a reusable analytical instrument

Extensible modular Design Toolkit of practicable, legally compliant dynamic consent design options participatively tested in secondary-use scenarios

Transfer contribution decision support and design instrument for use case specific dynamic consent solutions to support reuse of health data

6 References

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