Enabling data sharing through the Standard Health Consent. Health data privacy like Apple. But for everyone.



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Background

Self-generated health data from apps and wearables is providing new insights and critical information for personalised medicine and research.¹

The EHDS has introduced new concepts for sharing traditional and self-generated health data for personal care and research, but it's not clear how control is executed.²

Publication highlight: Gilbert et al., 2024 NPJ Digital Medicine (In Press <u>here</u>)

Meanwhile, industry leaders like Apple are a step ahead, providing customers with comprehensive data privacy tools.¹

Research focus

Can standardised digital consent enable health data sharing from apps and wearables?

How can digital consent be designed for balancing diverse citizens' needs and supporting the development of a fair and trusted data ecosystem?

Methods



Desk research



User needs research



Concept development



Iterative prototyping

Concept of Standard Health Consent

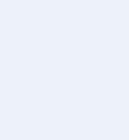
Features



controlled

Citizen

Broad and



Central storage

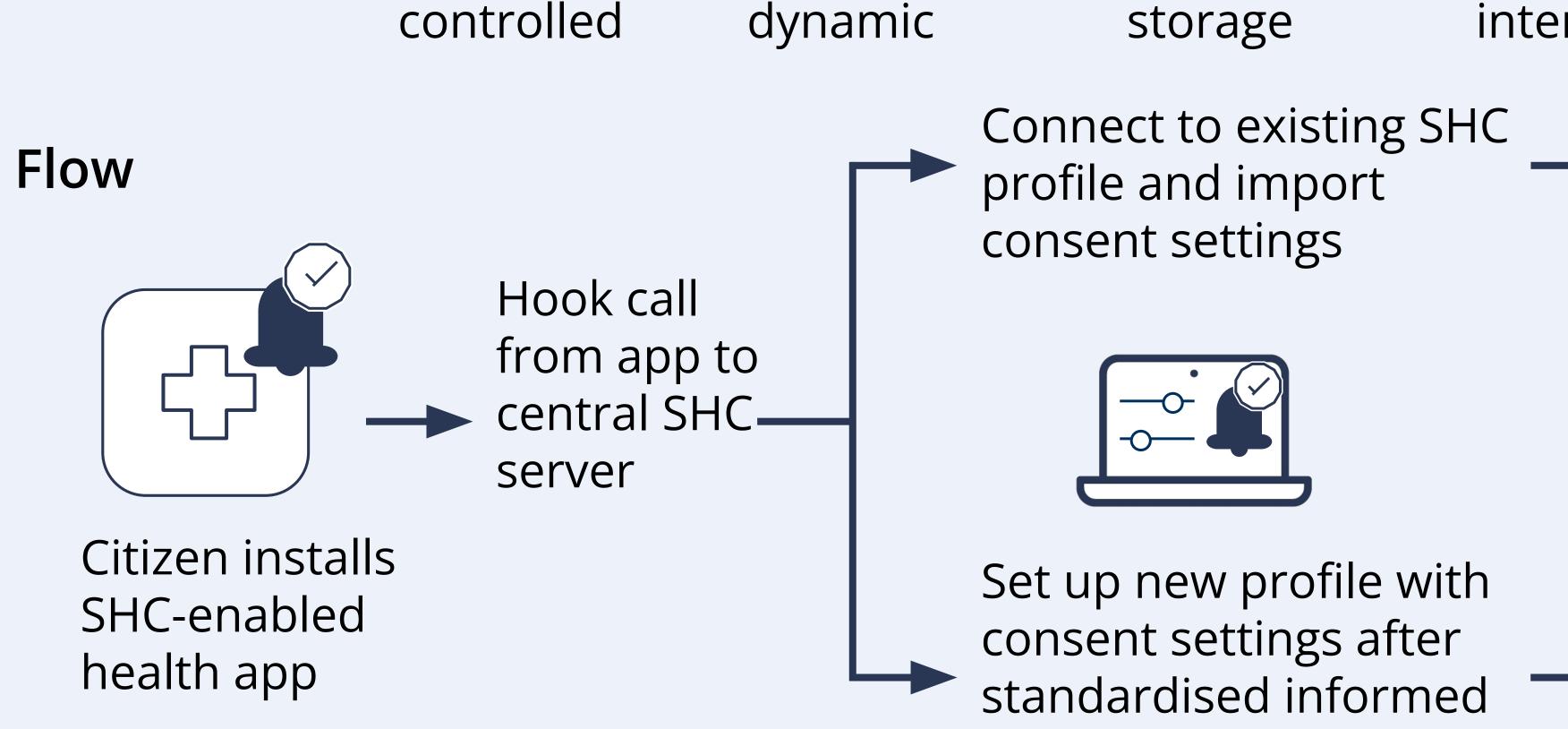
consent process



Publication highlight: Brueckner et al., 2023



Consistent interfaces

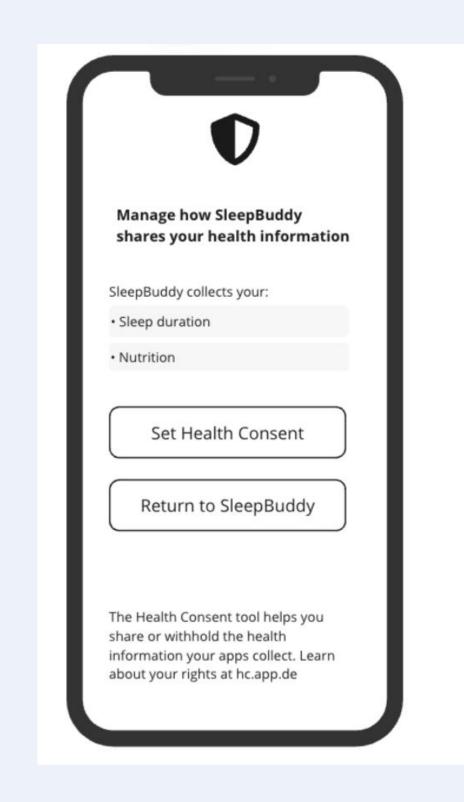


Consent settings saved on central server

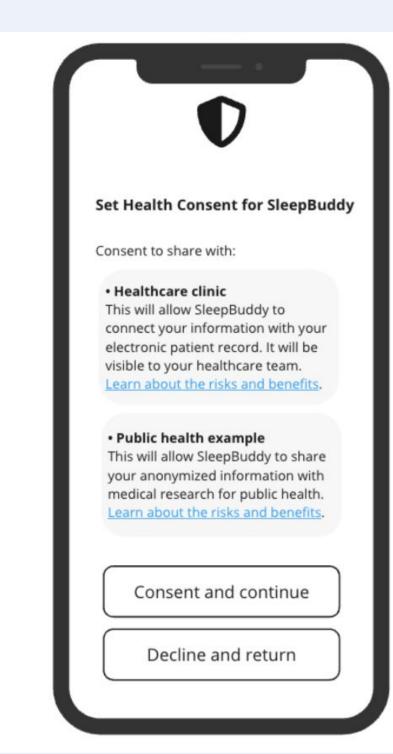
Citizen can change it at any time

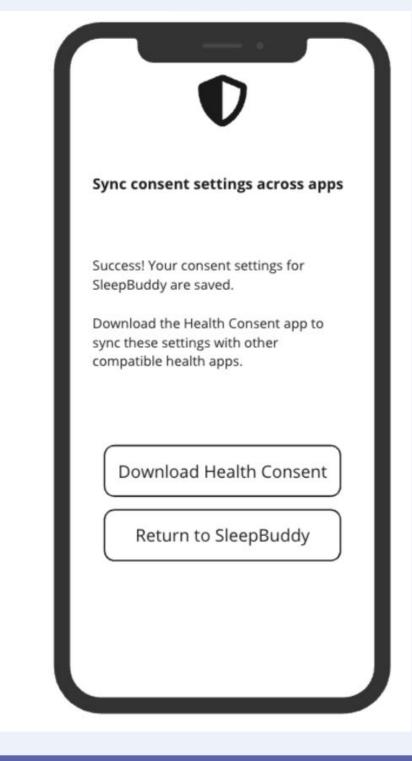
Next step: citizen-controlled health data sharing

Development of open-source modules for gathering and managing consent for health data sharing from apps and wearables.









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- ¹ Gilbert et al. NPJ Digital Medicine (In Press) https://doi.org/10.1038/s41746-024-01004-z
- ² EUROPEAN COMMISSION. Proposal for a regulation The European Health Data Space. (2022).
- ³ Brueckner et al. Mayo Clinic Proceedings: Digital Health

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