

DARE25-069 - FOXDenCity - Open Source Health Data Donation

Zusammenfassung

The digital transformation of healthcare has generated vast volumes of routine electronic health data that hold immense potential for advancing medical research. In Austria, the national EHR system ELGA offers one of Europe's most comprehensive and interoperable Real-World Data (RWD) infrastructures, covering 97% of the population. Yet, legal frameworks mandate explicit citizen consent for secondary use, making transparent and ethically robust "data donation" workflows indispensable.

Building on the Smart FOX flagship project—which established Austria's first citizen-driven data donation framework and the FOX BOX prototype—FoxDenCity aims to operationalize this "data donation box"- concept at production scale. The project will develop a reproducible, scalable, and open-source toolkit that enables ELGA-conformant data donation pipelines encompassing data extraction, harmonization, privacy-preserving record linkage, metadata export, and deployment automation. Core innovations include containerized FOX BOX components, a metadata model aligned with HealthDCAT-AP for EHDS compatibility, and ethics-compliant opt-in workflows integrating Austrian e-Government identifiers (ID Austria, bPK GH).

A pilot implementation at the Medical University of Vienna will validate the technical, ethical, and user experience dimensions with ~50 citizen donors with data sovereignty on premise. The toolkit's modular architecture ensures reusability across hospitals, research institutions, and national data spaces, facilitating secure and FAIR secondary use of RWD.

By transforming research prototypes into deployable open infrastructure, FoxDenCity will significantly strengthen Austria's position in citizen-driven medical research. The project contributes a foundational, interoperable component to a future Austrian Health Data Donation Space, empowering citizens to actively support medical innovation while maintaining sovereignty and privacy over their health data.

Wissenschaftliche Disziplinen:

Medical informatics (60%) | Public health (10%) | Biomedical engineering (30%)

Keywords:

Health Data Space, Electronic Health Records, Real World Data, Data Donation, Secondary Use, Standardization

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Weiterführende Links zu den beteiligten Personen und zum Projekt finden Sie unter
<https://wwtf.at/funding/programmes/ei/DARE25-069/>