

Citizens at the center of health data use: Value-added services from the "Health-X data-LOFT" health data space

Data sovereign, transparent, interoperable and federated applications for health data ecosystems based on Gaia-X principles — a project of the "Healthcare" department

The healthcare of the future will be based on the secure and meaningful networking and use of data. Citizens will be much better able to contribute to good treatment outcomes through informed action, as personal data from the secondary healthcare market (such as activity data collected through end-user devices) gains importance alongside data primarily collected by medical professionals. The aim of the "HEALTH-X dataLOFT" project is to place citizens at the center of the provision, use and control of their own health data within the framework of a health data space. Health data will be made usable according to Gaia-X standards.

Today, data from highly regulated primary care is securely stored in hospitals and physician offices. Due to their particular vulnerability and the low level of digitization in healthcare, they are rarely shared across facilities and sectors and integrated into overarching systems. However, with the German electronic patient record (ePA) and the Medical Informatics Initiative (MII), the Federal Ministry of Health and the Federal Ministry of Research have launched groundbreaking concepts to break the isolation of data and enable linkage.

In the second healthcare market, things are different: Personal health data, such as that collected by the many end-user devices available, is becoming increasingly important. Compared to clinical data, which can often only depict a snapshot, they provide a continuous picture of one's health, such as sleep patterns or exercise intensity. However, the current health tracking providers are often from outside Europe, which makes handling the data massively difficult or even impossible.

## Securely connect primary and secondary health data

However, the combination of the more accurate clinical data and the personally generated health data collected on a regular basis holds tremendous potential for improving health care from prevention to intervention to follow-up. The Health-X dataLOFT platform aims to make health data shareable. It will provide legitimized, open and federated access to data based on citizens' decisions, technologically implemented according to Gaia-X standards. This gives citizens access to and control over their personal health data — regardless of where it was collected.

## Technologies and architectures for a health data space

The research focus of the Fraunhofer Institute for Software and Systems Engineering ISST in this project is the development of technologies, processes and systems for building the data space and data-centric business solutions based on it. Fraunhofer ISST supports the development of the dataLOFT data space for the first and second healthcare market by developing and extending basic technologies as well as networking architecture layers.

Numerous partners are involved in the project, which is funded by the German Federal Ministry of Economics and Climate Protection: Charité — Universitätsmedizin Berlin (consortium lead), Bundesdruckerei GmbH, Fraunhofer Institute for Software and Systems Engineering ISST, Fraunhofer Institute for Digital Medicine MEVIS, Freie Universität Berlin, Hasso-Plattner-Institut für Digital Engineering GmbH, International Data Spaces e.V., IONOS SE, Medisana Space Technologies GmbH, OFFIS — Institut für Informatik, polypoly Enterprise GmbH, Siemens Healthcare GmbH, SVA System Vertrieb Alexander GmbH, TMF — Technologie- und Methodenplattform für die vernetzte medizinische Forschung e.V., Vilua Healthcare GmbH.

Detailed information on the project, which will run until fall 2024, is available on the website <a href="https://www.health-x.org">www.health-x.org</a>.



"In HEALTH-X dataLOFT you go from being a simple recipient of services to a determining and active partner. You get sovereignty over your health data and decide what happens to your sensitive data, how it is used and who may use it. Fraunhofer ISST has an important role to play in the technical, Gaia-X-compliant implementation of this requirement in the health IT solution landscape and thus in the reality of healthcare in the future."

Prof. Dr. Roland Eils, founding director of the "Digital Health" center at the Berlin Institute of Health at Charité Jniversity Hospital.