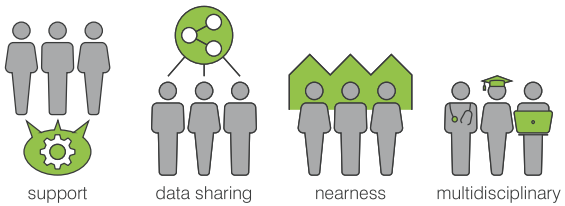
3.6. The Health Data Portal

Roadmap and goal

Only six months after the establishment of e/MTIC, Antonie van Noort (senior project manager at Philips Research) and his multidisciplinary team of IT experts, legal officers, privacy and security specialists, system architects, and a scrum master took off. Their target: Facilitate access for researchers to clinical data sets in a safe and scalable way to accelerate and improve research results.

Historically, data exchange for scientific research has been very cumbersome and has often been carried out in an insecure way. The increasing security and privacy requirements and upcoming regulations triggered the idea of developing a secure, privacy-conscious, scalable, FAIR and multi-centre data portal: the Health Data Portal (HDP).

HDP is a scalable collaboration platform that builds on existing initiatives to provide an infrastructure for sharing medical data from multiple institutions safely and allow researchers to collaborate on those data. It further allows medical data from different types of healthcare institutions to be shared securely and anonymously between hospitals, universities and industry.



Large datasets will enable scientists to discover and develop new hypotheses about human health and enable new applications in cross-disciplinary research or machine learning to contribute to the AI revolution in healthcare. HDP supports researchers to gain knowledge about more general diseases often treated in non-academic hospitals. Datasets that become available can be used to improve or develop medical devices. Therefore, HDP has the potential to become a platform that can lead to faster life sciences and health innovation.

Approach

The biggest challenge in the HDP project has been to get all requirements clear and all stakeholders aligned and work together in the same direction. The HDP team has formulated extensive requirements and specifications; what do we want and how do we achieve what we want? No less than 27 similar initiatives in the Netherlands have been examined to see what is out there already, discovering some useful modules and their owners. Amongst those owners are Philips with the "Clinical Data Lake" (CDL), the "anDREa" Digital Research Environment, an initiative of a.o. Radboudumc, and "ZorgTTP" for pseudonymizing data. Today, these parties are contributing as partners to realize HDP. Together they are optimizing and connecting the modules through a step-by-step process to achieve a mature solution for a significantly better research data infrastructure in e/MTIC and beyond.

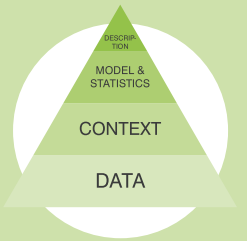
Results

Antonie: "We are about to launch the first version within e/MTIC so that researchers can get accustomed to the portal. The first pilot will be a single-centre study in close collaboration with anDREa and CDL. Organisationally, we aim to establish an independent HDP foundation that will provide data sharing services to not only e/MTIC but to many other stakeholders in the Healthcare research ecosystem. We do this in collaboration with the national Health-RI initiative."

What makes HDP unique is that it supports federated data sharing (and therefore the application of the FAIR standard) as well as providing a solution to share and process data which is not (yet) suitable for a federated approach. In addition, it offers a powerful data infrastructure which the average data user does not have.

A bright future for the Health Data Portal

The portal will be launched like a three-stage rocket, with increasing functionality and applicability in each stage. The first stage is a test of the portal concerning the three main clinical domains within e/MTIC.



The second stage involves multi-centre studies that will also cover other healthcare domains such as oncology. The pseudonymization expertise of ZorgTTP required for healthcare privacy, will be vital at this stage.

After that, the third stage requires the involvement of other hospitals and research institutes outside e/MTIC, further expanding scope and scale of the datasets. This fits very well in the Health-RI initiative, supported by the National Growth Fund, which creates a collaborating network of nodes across the Netherlands to build a national Health Research Infrastructure.

Antonie concludes: "I am proud of the collaboration between the e/MTIC partners, the creative and successful market quest for partners and portal modules, and my diverse team of specialists. Contributing to the acceleration of innovation through the Health Data Portal is a great way to spend the day."

Antonie van Noort