Letter of intent

File number: 175.2021.023
Grant: 2021/2022
Applicant
Title: Health Data Portal: From proof-of-concept to national platform

Abstract

NWO Domain: ZonMW
Research field codes:
16.60.00 (Artificial intelligence, expert systems);
21.10.00 (bioinformatics/biostatistics, biomathematics, biomechanics)

Involved research groups:
e/MTIC partners (TU/e, Catherina Hospital, Maxima Medical Center, Kempenhaeghe, Philips Research). With the proposed ambition, the number of partners (e.g., registries, public health institutes) will quickly increase (discussions are already ongoing).

Short description for investments:
The Health Data Portal (HDP) will be a unique scalable data science platform that can safely and securely share medical data for scientific research from different institutes and organizations. The platform serves academia, medical and public health institutes, and commercial partners, enabling a fast track to high-tech health innovations using engineering, data science, and AI. It allows previously isolated datasets to be linked and analyzed in a safe and privacy-preserving way. For instance, linking sleep data (home monitoring) with ECG data from the hospital will help our understanding of the relation between heart and sleep disorders, or linking childbirth data from the hospital with data from public health institutes will help us understand the effect of birth conditions on children’s cognitive development. Linking such datasets will allow researchers to ask new and deeper questions and contribute to breakthroughs in prevention, diagnostics, and treatments.

The design of the HDP has set the highest priority to GDPR-compliance without compromising research requirements by using trusted third parties that process and handle data requests (e.g., double pseudonymization processing). A proof-of-concept of the HDP is currently being built by the e/MTIC consortium, leveraging existing technology (all suppliers have created and signed their statement-of-work), but in order to benefit health research on a national scale, we would like to turn the current proof-of-concept HDP into a national infrastructure for sharing health data to enhance data science and medical research. This requires additional investments for hardware and software and the creation of data access processes to include data from external registries (e.g., Perined, NHR, KNL), personal data ("donate your data" options), administrative data (e.g., insurance companies), and public health data (e.g., from GGD). These investments will be used for material and personnel to make the HDP technically and operationally ready for large-scale deployment (e.g., develop databases, data lakes, VREs, data catalogues, search engines, portals, workflows, process flows, etc.). This includes the development of a meta-data catalog (for FAIR principles) that will ingest and curate data from the e/MTIC partners and beyond.

Roadmap GWI:
We submitted our HDP to GWI in 2020 and we were very happy that we were listed in the national roadmap (confirmed by an email of Alice Dijkstra, NWO coordinator GWI, on December 24, 2020), but NWO unintentionally forgot to organize us in a group that would drive the roadmaps. We have tried to correct this, by joining the roadmap of prof. dr. W.J. Niessen (Federated Dutch Cohort Infrastructure), but he was unable to include us. The partners of e/MTIC are now financing a proof-of-concept and HealthRI is acknowledging and supporting the HDP as part of the national data platform and e/MTIC as a regional node.

Organisation responsible for the application
Confirm letter of intent
With submitting this form via ISAAC I declare to have filled in this form completely and truthfully.

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Applicant