SPHN Working Group for the Federated Query System

Version and date: Version (V2), 20 June 2022

Starting position

The Swiss Personalized Health Network (SPHN) promotes the development, implementation, and validation of coordinated infrastructures to make health data interoperable and shareable for research in Switzerland. As part of the SPHN initiative, various efforts are currently underway to harmonize and define data standards in order to ensure the interoperability of health-related data, with a specific focus on data from the five Swiss University Hospitals (UH). In the first funding phase, the SPHN Data Coordination Center (DCC) and the SPHN partners established the Federated Query System (FQS), which enables researchers to verify the feasibility of their project by searching for fully anonymized clinical information across all five university hospitals. The system is set up in a decentralized way, allowing hospitals to retain full control over their data. The following milestone were achieved:

Development phase:

- The FQS system was established in all 5 UHs;
- Over 80 Mio data elements of 490'000 patients, who signed a general consent, were loaded;
- Monthly data loads were established at all 5 UHs;
- The FQS collaboration agreement was signed by all 5 UHs and SIB Swiss Institute of Bioinformatics and the FQS Executive Board was formed. An FQS Acceptable Use Policy to be signed by all users was developed and approved by all parties;
- The Clinerion software was adapted to the SPHN needs (e.g., regarding data privacy: results smaller than 10 patients are not displayed; ICD-10 GM and CHOP are made available in English; Two-factor authentication using institutional email addresses was implemented; etc.).

Testing phase:

- Selected users of the 5 UHs tested the system and provided feedback on the system;
- The FQS was opened to all users from the 5 UH in Nov 2021.

1st of May 2022, the SPHN FQS entered the operational phase, during which the system will be opened to biomedical researchers from all swissuniversities institutions. Thanks to the FQS, SPHN has identified a series of critical issues, among them the need for more standardization (i.e., for data as well as the IT architecture setup) and a better quality assurance on the side of the data providing institutions.

In particular, the following challenges and gaps have been identified and need to be tackled:

- In some UH, LOINC and UCUM have not been introduced at the source (i.e., in the main labs of the hospitals), but mapped in the CDWs – a process that is error prone and potentially leading to false codes as soon as changes in the laboratories are introduced without communication to the CDWs;
- Substance amounts of medications are not available in the CDW and are individually computed before data delivery to SPHN projects;

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- Diverse IT architectural setups of the FQS in the individual hospitals make the maintenance of the system challenging (e.g., only delta-loads possible in one UH, since a full load would require 5 days);
- Ideally, a test system is needed to test changes in the FQS system (data and new functionalities) before deploying them to the system in production;
- USB currently does still not offer the possibility for their researchers to include an AAI-link in their SWITCH edu-ID profile (required for authentication purposes on the SPHN side).

Mission

Coordination and alignment of all activities around the SPHN FQS in the five UHs in the operational phase including further development of the system.

Tasks and timeline of the Working Group

The timeline for the WG to complete the mandated until the end of SPHN funding phase

[1] Support a potential alignment of the FQS IT architecture across the 5 UHs

[2 Evaluate the setup and operation of a test system

[3] Implement an interface extension for integrating the amounts of active ingredients of a drug into the FQS

[4] In close collaboration with the DASAQ Working Group: improve the data quality and data availability in the FQS

[5] Roll out of the data load protocol

Composition of the Working Group

The HIT-STAG nominated the following representatives of the UH:

- Insel: Reinhard Dietrich
- HUG: Pierre Dethare
- CHUV: Yves Jaggi
- USZ: Josip Matic
- USB: Michael Hadorn

The DCC provides project management support (up to 0.2 FTE). The WG is chaired by the DCC; Roger Mathis (from IT-Logix) is responsible for the project management and co-chairing the WG.