

FEDERATED QUERY SYSTEM

ACCEPTABLE USE POLICY

Introduction

The federated query system (the **Query System**) is a coordinated data infrastructure of participating Swiss university hospitals (**University Hospitals**) enabling effective exchange of information for biomedical research purposes about health-related data stored at each University Hospital.

The aim of the Query System is to allow researchers of eligible institutions (**Researchers**) to know whether and where enough patients or patient data potentially suitable for a specific biomedical research question exists at a University Hospital in order to verify the feasibility of their project.

The Query System allows Researchers to search the clinical data warehouse of the University Hospitals. The Query System will only return aggregated query results (patient counts) and limited summary statistics based on de-identified data (the **Data**). The Query System is not designed to share or access personally identifiable patient data.

The Query System is regulated by an Institutional Collaboration Agreement entered into by the University Hospitals and the SIB Swiss Institute of Bioinformatics, which defines the respective responsibilities of each institution involved in the Query System. In accordance with the Institutional Collaboration Agreement, each institution having access to the Query System is in particular responsible for monitoring and verifying that its own researchers are authorized to use the Query System.

1. Purpose and Scope

This Query System's use and access policy (the **Policy**) defines the rules that each Researcher must comply with when accessing and using the Query System. It applies to all Researchers who use or have access to the Query System.

2. Executive summary

- The Query System may only be used by authorized Researcher, for the biomedical research project(s) they carry out for their institution.
- It must not be used to try to re-identify individuals by any means.
- Security and technical measures have been implemented to restrict certain non-authorized use and protect the Query System infrastructure and the Data, which shall be complied with and shall not be circumvented.
- The Query Platform shall not be used for other purposes or in any other manner than indicated in this Policy, even if such use would technically be possible.
- If security requirements are not met by the researcher, it may engage the liability of the researcher and the authorized institution.

3. Access limitation

Access to, and use of, the Query System and/or the Data is limited to Researchers who have:

- (i) been verified being part of an institution allowed to use the Query system¹;
- (ii) a valid SWITCH edu-ID² account linked to SWITCHaai³ (Authentication and Authorization Infrastructure); and
- (iii) accepted this Policy and comply with its terms.

Researchers who have left their institution shall immediately stop accessing and using the Query System, even if their credentials have not yet been revoked.

4. General Undertakings

All Researchers must:

- a) use the Query System and the Data **only to the extent required for the scientific biomedical research projects of their institution on which they are directly involved**. All other uses are strictly forbidden;
- b) comply with the security requirements specified in Section 5;
- c) not attempt to re-identify patients or use the Query System (by itself or in conjunction with other tools or datasets) in any other manner which could permit to partially or wholly rebuild the patient records and/or identify patients (e.g. through an excessive number of searches or too narrow searches resulting in data subject becoming identified or identifiable);
- d) not use the Query System to compare the numbers among different institutions for purposes not related to the feasibility question of a research project;
- e) not use the Query System on behalf of unauthorized personnel or third parties, nor permit them to use all or part of the Query System or the Data, nor share such Data, publish it, or in any other way make it available to outside entities or individuals;
- f) report all irregularities observed regarding the use of the Query System and respective Data. Such report can be communicated to the Data Coordination Center of SIB Swiss Institute of Bioinformatics (dcc@sib.swiss), the Query System's administrator; and
- g) use the Query System and the Data in accordance with all applicable law, including data protection and human research laws, and ethical guidelines.

5. Security Requirements

Researchers must comply with the following **security requirements** for the use of the Query System:

¹ Institutions, who are allowed to use the Query System can be found here (<https://www.switch.ch/de/aai/participants/homeorgs/>)

² <https://www.switch.ch/edu-id/>

³ <https://www.switch.ch/aai/>

- a) take all the necessary actions to **secure their account** and preserve the confidentiality of their respective credentials that are necessary to access the Query System. In particular, Researchers must not share their credentials with any other person or store them in clear text in password directories;
- b) use **strong passwords**, which must be changed periodically, and manage a second factor required for the **Two Factor Authentication**;
- c) if personal computers are used to connect to the Query System, these machines must satisfy internal minimum security requirements provided by each institution, such as having recent security updates and malware protection (anti-virus software);
- d) not circumvent any access protection or restriction mechanism, nor use or try to gain access to any Data which they are not entitled to access;
- e) take all necessary actions to **protect the confidentiality, availability and integrity of all Data**. In particular, Researchers must not share such Data with unauthorized personnel, publish it, or make it available to outside entities or individuals;
- f) not install or use any software that might harm other Researchers, projects or the Query System;
- g) not install any software to automatize the generation of queries in the Query System;
- h) inform the SPHN Data Coordination Center of SIB Swiss Institute of Bioinformatics (dcc@sib.swiss) immediately if the confidentiality of their credentials is compromised, or if any other issue related to data integrity or security is identified and assist, to the best of their ability, with any investigation.

6. Monitoring

The Query System's administrator reserves the right to monitor activities on the Query System on an individual basis and compliance with this Policy.

Each institution may also monitor activities of its own researchers on the Query System on an individual basis and compliance with this Policy.

7. Non-Compliance

Compliance with this Policy is mandatory. A Researcher who violates or circumvents this Policy will have her/his access revoked, and her/his host institution will be notified immediately (disciplinary actions may follow).

Some violations may also constitute violations of laws or regulations and result in civil or criminal penalties.