



The Swedish Twin Registry

Policy Statement Regarding Collaboration



**Karolinska
Institutet**

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The Swedish Twin Registry (STR) is the largest and most comprehensive twin registry in the world (Zagai U, Lichtenstein P, Pedersen NL, Magnusson PKE. The Swedish Twin Registry: Content and Management as a Research Infrastructure. *Twin Res Hum Genet.* 2019;22(6):672-680).

Founded in 1961, the registry covers all like-sexed twin births since 1886, and all twin births (like- and unlike-sexed) since 1906. There are currently 107,000 pairs of twins registered, of which both members of 77,000 pairs are alive, with monthly updates concerning vital status and addresses. We also link information from national health registries about hospital discharges, drug prescriptions, tumours, and causes of death. Furthermore, there are extensive epidemiological data (on exposures, symptoms and diseases collected through questionnaires or interviews) on all participating pairs born 1992 or earlier. For twins born later, parents to 9-year old twins have been contacted for interview in the CATSS study. From 2020 and onwards the CATSS data collection is based on web-questionnaire instead of a telephone interview.

Access to the STR

STR constitutes a national research infrastructure open to projects initiated from both academic and industry-based researchers. Regardless of the type of research interest, all potential projects with data access requirements must be reviewed and approved by the steering committee of the STR. Types of requests for access include:

1. aggregated summary tables or statistics from the STR
2. pseudonymised (coded) files of raw and/or transformed data from the STR
3. access to identifying information for new data collection
4. access to biobank samples

All requests require, that a short application is submitted to the STR, by an applicant with a PhD, MD or equivalent degree. Prior to submitting an application, interested researchers may contact the STR to obtain further information (such as summaries of prevalence) necessary for evaluating feasibility. For points 2-3 above, data is only provided when approvals by the Swedish Ethical Review Authority are in place. If the applicant is not based at a Swedish university, we require that s/he has a collaborator based at a Swedish university. This is to assure that there is Swedish ethical permission and that the Swedish research community benefits from our national resource. All applications are handled on a first come, first serve basis, meaning that the steering committee will review and assess the applications in the same order as they are submitted to STR. After approval by the STR steering committee, contracts will be signed, and data delivered after a payment agreement is arranged.

How to apply

Step 1: prepare documents

1. A detailed and complete description of the project comprising 3-5 pages, including:
 - a) specific aims
 - b) general background (including relevant literature references)
 - c) requested variables with inclusion and exclusion criteria
 - d) methods
 - e) description of the research group
2. CV of the PI (Principal Investigator)
3. Ethical application and ethical approval. For projects in which study persons are to be contacted, it is recommended that the STR steering committee reviews both information letters and informed consent formulations before these documents are sent for ethical review.

Step 2: web application

1. Go to the web-based tool for core facilities at KI, iLab, to register/login:
<https://karolinska.corefacilities.org>
2. Fill out the STR application form and attach the documents (from step 1-3 above).

Costs for accessing data from the STR

The maintenance and development of the Swedish Twin Registry is enabled through base support from Karolinska Institutet and the Swedish Research Council. Additional developments of the STR have been supported by user initiated and project specific grants to public granting agencies. Any research based on STR data must be self-supporting. There are access fees to obtain access to STR data, which are determined based on the nature and complexity of the data.

Access to data collections undertaken and financed by external users (PI's) demand that these PI's are offered involvement in the project and papers emanating from these materials up to five years after respective data collection are complete. Help with data analysis is charged on an hourly basis.

Access and costs for biological samples from the STR

The TwinGene study collected blood DNA and serum from 12,600 twins born 1958 or earlier. It was finalized during 2008. For younger twins (born 1959 or later) DNA has been collected from saliva samples. All samples are stored in the KI biobank. Use of these biological data is encouraged. However, the samples are finite and access has to be carefully considered and coordinated by the STR. Cost for access depends on amount/volume and whether the measurements are undertaken on a large majority of the samples (and thereby can be considered a general enrichment of the registry when reported back to the STR) or if it is cherry picked/smaller proportion of samples. Current price list is available on the STR homepage.

Other requirements

If a researcher conducts a data collection, after approval from the steering committee, the STR requires that the following information (in the form of copies or duplicate samples) shall be shared with the registry:

1. information regarding zygosity
2. suitable biological measurements
3. suitable biological samples, stored in the KI Biobank

Depending on whether the data or samples can be considered to be of general research interest, the STR may co-sponsor the collection.

Scales that are derived from any data in the STR and used in a publication should be sent to str-research@meb.ki.se, for inclusion in the STR database. This information will then be available for other researchers.

For questions or more information: str-research@meb.ki.se

Patrik Magnusson, Associate Professor
Director of the Swedish Twin Registry

The Swedish Twin Registry is the largest of its kind and has become an invaluable resource for medical research. The Registry is a national research infrastructure supported by the Swedish Research Council and is managed by Karolinska Institutet.

Karolinska Institutet is one of the world's foremost medical universities. Our vision is to advance knowledge about life and strive towards better health for all. In Sweden Karolinska Institutet is the single largest centre of medical academic research and offers the country's widest range of medical courses and programmes. Since 1901 the Nobel Assembly at Karolinska Institutet has selected the Nobel laureates in Physiology or Medicine.



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