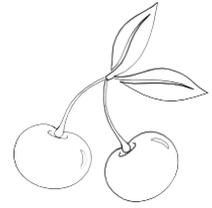




The Swedish Twin Registry

Karolinska Institutet



Swedish Twin Registry Policy Statement Regarding Collaboration

As described by Lichtenstein et al., 2002, Pedersen et al., 2002 and Lichtenstein et al., 2006, the Swedish Twin Registry (STR) is the largest and most comprehensive twin registry in the world.

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 89,000 pairs of twins registered, of which both members of 65,000 pairs are alive, with regular updates concerning vital status, addresses, hospital discharges, tumors, and causes of death, through subscriptions to national registries. Furthermore, there is extensive epidemiological data (exposures, symptoms and disease through questionnaires or interviews) on all pairs born 1986 or earlier, for most individuals involving 30 year baseline to follow-up information. Furthermore, twins born since 1992 have been or will be contacted with a telephone interview with the parents of twins as they turn 9 (CATSS).

Access to the STR

Because the STR is an (inter)national resource, we are receptive to collaboration with academic and industry-based researchers. Regardless of the type of research interest, all potential collaborations or data access agreements must be first reviewed by the Steering Committee of the STR. Types of requests for access include:

1. aggregated summary tables or statistics from the STR
2. anonymized files of raw and/or transformed data from the STR
3. above data plus linkages to health registries
4. access to identifying information for further collection of new data

In all cases, a short application must be submitted to the STR, by an applicant with a PhD, MD or equivalent degree. Prior to submitting an application, interested researchers may contact the coordinator for the STR to obtain information (such as summaries of prevalence) necessary for evaluating feasibility. Other summary tables may be obtained without other approvals (i.e by ethics committees / institutional review boards), although an access charge will be applied (see below). For points 2-4 above, data will not be provided until appropriate approvals by ethics committees / institutional review boards are obtained. 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 the Swedish research community benefits from their national resource. After approval by the STR steering committee, a contract will be drawn up, and data provided after a payment agreement is arranged.

Contents of the application

1. Fill in the Data Request Form. The document is available for downloading next to this policy document.
2. A detailed and complete description of the project comprising 3-5 pages, including:
 - a) specific aims
 - b) general background (including relevant references to the literature)
 - c) data requested with inclusion and exclusion criteria
 - d) methods
 - e) types of analyses, including a discussion of power as appropriate
 - f) description of research group
3. CV of the PI (Principal Investigator)
4. Ethical vetting and ethical consent from a **Swedish Ethical Review Board** (when applicable).

Costs for accessing data from the STR

The maintenance and basic development of the Swedish Twin Registry is enabled through base support from Karolinska Institutet. Many of the recent developments in the STR were and are supported by researcher initiated grants to public granting agencies (most notably, various institutes within the NIH). Any research based on STR data must be self-supporting. There are access fees to obtain access to STR data, which are set based on the nature of the data. Costs for archived data (i.e. base data from initial ascertainment questionnaires by the registry, the SALT and STAGE studies and record linkages to national health registries), are based on a modest flat fee and hourly rates for data extraction by the STR database administrator.

Access charges for data from the most recent screening efforts (the BIRTH (PI Sven Cnattingius), SALTY (PI Patrik Magnusson), and CATSS (PI Paul Lichtenstein) studies as well as for the recently performed GWAS of the TwinGene study) are based on the actual item costs for data collection. The PIs of these efforts should be offered to be involved in projects and papers emanating from these materials during the 5 years after data collection are complete. A base package of information (zygosity, age, sex, educational attainment) is included without further cost. 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, but because the samples are finite, access has to be carefully considered and coordinated by the STR. Cost for access is based on the number of samples used. For smaller studies, the cost for each sample is 300 SEK. All results (genotypes, biomarker levels etc) should, after publication, be transferred back to the STR.

During 2009-2011, the STR has collected saliva samples from the twins born 1959 or later. As for the TwinGene study, use of biological data is encouraged, but because these samples include even less DNA, the STR will be more careful when approving use of samples. Cost for access will be 300 SEK for each sample. All results (genotypes) should, after publication, be transferred back to the STR.

Other requirements

If a researcher has been given access to identifying information that allows researcher initiated data collection, the STR requires that the following information (in the form of copies or duplicate samples) be shared with the registry:

- 1) information regarding zygosity
- 2) biological samples should be stored in the KI Biobank

Depending on the purpose of the study, the STR may co-sponsor the costs of sample collection.

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

Collaboration with industrial partners

The STR realizes that the long term goals of developing a biobank on all twins (over 100,000 individuals) can only be met by mutually advantageous agreements between the STR and several funding sources. To that end, the STR has participated in a number of industrial collaborations.

The STR has had several successful collaborations with industrial partners. Astra Hässle AB and Pharmacia AB supported the STR during the collection of pilot data for SALT screening (in 1996-1997) through unrestricted grants. AstraZeneca has also given generous support to the STR for “registry enhancement” and “biobank establishment” (in 2001), and subsequently, project specific grants for “extended research”. Extended research grants have taken two forms:

- 1) secondary analyses of existing data and
- 2) industry initiated data collection (including biological samples).

Further inquiries and applications:

These should be sent to: tvillingregistret@ki.se

For the Steering Committee of the Swedish Twin Registry
Patrik Magnusson, Assistant Professor
Director, the Swedish Twin Registry