



Data application form

Name of applicant/project manager

e-mail

Affiliation

phone no.

Co-applicant(s)

e-mail

Project title (*max 200 characters*)

Project description/abstract (*max 200 words*)

Propose start date (dd-mm-yyyy)

Proposed end date (dd-mm-yyyy)

Generally, data will be uploaded at a secure twin research server at SDU. In some cases, data can be uploaded elsewhere, but the applicant must explain such needs and where to upload data. The Management of the Danish Twin Research Center will decide whether the request can be met.

Attachments (*required documents)

Project protocol*

CVs of applicant/project manager*

Approvals (if obtained in advance)

The Danish Data Protection Agency

The Committee on Health Research Ethics

Legal Services (applicant's institution)

Other relevant approvals. If other, please describe

Other relevant attachments. If other, please describe

Application guidelines

The project description must be 3-5 pages and contain the following information:

1. General background (including relevant references to the literature cited)
2. Purpose (including hypotheses)
3. Description of the data applied for
4. Outline of data management plan (i.e. how are the data to be handled during and after the project is completed? Which institution will be data controllers? Which institution will be data processors?)
5. Research method(s)
 - a) Questions (interview forms, if any, may be enclosed)
 - b) Collection of biological material
6. Types of analyses including discussion of required statistical power
 - a) Analysis plan (who, how)
7. The names of the research team including CV (max. 2 pages) for the applicant/project manager
8. Co-operation plans and project time schedule
9. Publication plan
10. Approval by the Danish Data Protection Agency/Legal Services of applicant's institution, and if requested the Committee on Health Research Ethics
11. Requested data from the Danish Twin Registry:
 - a) Summary table(s)
 - b) Anonymous data
 - c) Identifiable data (from own data collection) +/- biological samples
 - d) Statistical instructions

The study must in all essentials keep to its protocol, and new studies must never be started without approval from the Scientific Board of the Danish Twin Registry.

When the study protocol is approved, the appointed contact person from the board will arrange practicalities regarding Data Use Agreement and data access etc. according to the regulations.

Other terms

Collection of new data

If a research project entails a collection of new data as a result of contact with the twins, the Scientific Board of the Danish Twin Registry must be informed of the following:

1. Participant status and his/her reason for non-participation
2. Zygosity diagnosis of twins participating in clinical studies, if such a diagnosis is not obtained in collaboration with the Scientific Board of the Danish Twin Registry.
3. Contact with any twins beyond the time period described in the protocol must not take place until approvals from the Scientific Board of the Danish Twin Registry has been obtained.
4. Letters to twins must always include the co-signature of the project's contact person from the board.
5. Questionnaire surveys must not contain more than one reminder notice to each potential participant unless otherwise agreed with the Scientific Board of the Danish Twin Registry and the Committee on Health Research Ethics.
6. Data will generally be made available to researchers in anonymized form. Identification information may, however, be made available if contact with project participants is required.

Biological material

If collection of biological material is part of the project, a sample can be given to the Danish Twin Registry for storage in our biobank.

Biological material from twins can only be used for the purpose to which it has been collected unless the study participants have consented in allowing the use of their material in other research projects. In that case the biological



material may be used in other projects after the conclusion of the original project, but only if approved by the Scientific Board of the Danish Twin Registry and the Committees on Health Research Ethics.

Project conclusion

When the project is ended the research data (both personal data and biological material) can be stored at the Danish Twin Registry, with the register obtaining any approvals needed from the Legal Services (SDU RIO). The storage of all data at the Danish Twin Registry replaces the claim of data to be deleted/destroyed or anonymized in accordance with the guidelines.

At project conclusion all collected data can be given to the Danish Twin Registry in order to ensure an optimal utilization of data by the research community. This also applies to new scales or indices estimated on data from the Danish Twin Registry and used in published studies.

The project team has the right to use the data resulting from the project during the entire project period and five years after project conclusion. After this date, data that have been delivered to the Danish Twin Registry may be made available to other researchers, but only after the Scientific Board of the Danish Twin Registry has advised the researchers, who originally procured the data.

Data collected by or resulting from a research project will never be passed on to third parties if the research project is active. In general, information on zygosity, vital status, may be passed on to third parties.

Dissemination of results

All manuscripts must be approved by the contact person from the board before submission. The contact person is under obligation to comment on manuscripts within a reasonable time limit. A copy of the publications (including abstracts) resulting from the research project must be forwarded to the Danish Twin Research Center.

The following acknowledgement line must be used on all reports, publications, and other materials resulting from use of data from the Danish Twin Registry:

“Data used for this research was provided by the Danish Twin Registry, University of Southern Denmark. The findings, opinions and recommendations expressed therein are those of the author(s) and are not necessarily those of the Danish Twin Research Center.”

Data fees

The fees for carrying out a research project using data from the Danish Twin Registry are covered by the project team. This means that you should allow for such fees when drafting your project budget.

The price for your dataset will depend on the time our data managers spend on assisting you and constructing your dataset. Usually, the price will be DKK 1,200 per hour.

In addition, there is an annual fee of DKK 5,000 if you work on our server, including storage space.

For each project, the project team and the management of the Danish Twin Research Center will agree on the fees.