CENTRE OF REGISTERS
VÄSTRA GÖTALAND

This information is filled in by
Centre of Registers Västra Götaland

Reference number

Date received

Application for register data from quality registers for research purposes

Which register does the application relate to?

Select register

The form and procedure apply to register representative associated with Centre of registers Västra Götaland for which Region Västra Götaland has central personal data responsibility (CPUA in Swedish).

Click here for a list of registers associated with Registercentrum Västra Götaland.

Click here for information about applying for data from other quality registers.

Please contact relevant register representative before the application is sent to the Centre of Registers Västra Götaland. Contact information for the registers can be found on each register's website. An approved ethics review application is required for research purposes for the disclosure of register data containing sensitive personal data. Note that the information in this application must correspond to that in the ethics review application.

Depending on the scope of the work, a fee may be charged. It may also be necessary to draw up a supplementary agreement. If this is the case, you will be contacted by a register representative.

Send the application to:
rc.datauttag@vgregion.se

or

Centre of Registers Västra Götaland
413 45 Göteborg

Information about the form

This form aims to facilitate processing of requests for disclosures from the registers, but you may of course request public documents from Region Västra Götaland in other ways under the principle of public access.

Information about the research group and billing information

1. Research principal

Please note that the research principal must be the same as in the ethics review application.

2. Authorized representative of the research principal

For example: head of department, operations manager, clinic manager, manager or equivalent.

Name:

Title and role:

Organization:

Address:

Mobile phone: **E-mail address:**

3. Invoicing address

Invoicing address:

CRN:

Reference:

4. Lead researcher

Please note that the lead researcher must be the same as in the ethics review application. A data processing agreement (DPA) is required if the lead researcher works in an organization other than the research principal's; the agreement is then attached as an appendix to this application.

Name:

Organization:

Mobile phone: **E-mail address:**

5. Recipient of data on behalf of the research principal

If the recipient of the data is the same as the lead researcher, this item may be left blank. A data processing agreement (DPA) is required if the recipient works in an organization other than the research principal's; the agreement is then attached as an appendix to this application.

Name:

Organization:

Mobile phone: **E-mail address:**

6. Is the project carried out in collaboration with industry?

If the research project is carried out in collaboration with industry, an agreement between the company and the principal concerned must be attached.

Click here to see a collaboration agreement between the Swedish Association of Local Authorities and Regions (SKR) and industry regarding a quality register.

◯ **No**

◯ **Yes, agreement attached**

Information regarding data linkage

Centre of Registers Västra Götaland can assist in linking data from several registers. If data is to be matched from several national quality registers, separat applications to each register is needed. For registers with central personal data responsibility (CPUA) outside Region Västra Götaland, the application is made to the relevant CPUA in accordance with their procedures for data extraction.

7. Is the data to be linked with data from other registers?

Data applications regarding more than one register, a separate and approved data application is required for each register. State registers.

8. Is the data to be linked with data from another authority?

E.g. the National Board of Health and Welfare or Statistics Sweden. Enter the relevant authority and contact information for administrators together with any reference number below. Details of key variables are given in section 11.

Information about the research project

9. Project title and short description

Title:

Summary of project description:

Background, scientific hypothesis and objectives and work plan. Always attach the project plan.

10. Decision from the Ethical Review Authority

The Ethical Review Authority's approval of the intended processing of personal data is a requirement for data extraction for research to be approved and issued, but it does not replace the confidentiality review carried out by the disclosing authority (CPUA). Attach a copy of the application and decision.

Reference number for the decision by the Ethical Review Authority:

Data extract

11. Selection

Which selection will apply to the data? It could concern date intervals, diagnoses, gender, region, age and so on. Be as specific as possible. The search is facilitated if the register's variable name and associated variable values are used in describing the extract, e.g. Surg_Age ≥ 65 and Surg_County=Stockholm. The selection must be stated in the approved ethics review application.

Will the selection be made by linking the incoming file from the customer?

◯ **No**

◯ **Yes, state source:**

If the data is to be linked with data from another authority, what variables should the matching be carried out on? *(e.g. personal identity number, date of operation)*

Variables:

Other requests:

12. Requested variables

The variables requested must be stated in the approved ethics review application. They may also be attached as a separate document.

13. Is the data to be identifiable via the personal identity number in the extract?

When linking with data from an authority and a personal identity number is required, this must be described in the approved ethics review application.

◯ **No; only the serial number and the code key can be deleted three months after the disclosure.**

◯ **No; only the serial number, but the code key needs to be saved for more than three months after the disclosure.**
Specify how long the code key will be saved for, justify this and specify on which page in the ethical review application this is described:

◯ **Yes; personal identity numbers are required.**
Justify and state on which page in the ethics review application this is described:

14. In what file format do you want the data to be delivered?

◯ **SAS**

◯ **Excel**

◯ **SPSS**

◯ **Tab-separated text file**

◯ **Other:**

Conditions for disclosure of register data

15. Appendices

1. Ethical review application, including appendices. Mandatory.
2. Decision from the Ethics Review Authority. Mandatory.
3. Project plan. Mandatory.
4. List/description of required variables and current selection. Optional.
5. If the recipient of the data works outside the research principal's organization, a written DPA must be signed and attached. Mandatory if applicable.
6. If the research project is carried out in collaboration with industry, the agreement between the parties must be attached. Mandatory if applicable.

16. Information for personal data processing

Remember to take the following into account when processing personal data for research purposes:

a. The data extract may only be used for the purposes described in the approved ethics review application. If the customer wish to use the material for any other purpose, a new ethics review and a new disclosure review must be made.

b. Delivered data must be stored in a secure manner so that it remains inaccessible to unauthorized persons.

c. If personal data is to be processed by a person other than the lead researcher, a written data processing agreement (DPA), which must also describe the conditions for the use of the data, must be signed by the principal and the other workplace.

d. The results may only be published in such a way that the identity of individuals is not revealed.

e. Delivered data may only be used for as long as it is needed for the stated purpose. After this period, the material must be archived/deleted in accordance with the regulations of the research principal. All working copies must be destroyed.

f. Correct references to the register must be made in the method sections and in acknowledgements in the publication(s).

g. A final report of some sort, e.g., a scientific article, should be sent to the register after the project has been completed.