|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| The registry or the registry centre’s logotype/name  and the CPUA authority’s logotype/name |  |  | Insert the registry or the registry centre’s logotype/name and the CPUA authority’s logotype/name |  |  |
|  |  |  |  |  |
|  |  |  |  |  |

# Application for registry data from quality registries for research purposes

**Submit application to: Insert current contact information for the registry incl. address**

**Information provided by: Insert current contact information**

**For more information on definitions, please see the application to the Ethical Review Boards.**

## Ordered by (authorized representative for principal investigator)

|  |  |  |  |
| --- | --- | --- | --- |
| Name |  | Phone |  |
| Title or role |  | Organization |  |
| Address |  | Mobile phone |  |
| Email address |  |  |  |
| Billing address incl. any reference |  |  |  |
| Co-applicant(s),  if any |  |  |  |

## Who will the extracted data be released to (person responsible for implementation of project)

|  |  |  |  |
| --- | --- | --- | --- |
| Name |  | Phone |  |
| Title or role |  | Organization |  |
| Address |  | Mobile phone |  |
| Email address |  |  |  |

## Title and short description of project

|  |  |
| --- | --- |
| Title |  |
| Summarized project description, i.e. background, research topic and objectives/working schedule  (also enclose project plan) |  |
| Project end date |  |
| Chief researcher | |
| Are there any decisions from the Ethical Review Board (EPN)?  Yes Ref no.: (enclose copy) | |

|  |
| --- |
|  |
| Which quality registry/registries would you like data from?  |  |  | | --- | --- | | Specify the registry or registries |  |  Would you like support from the registry or registry centre (e.g. data processing or statistician assistance)*?* |
| If yes, describe type of support or assistance |
|  |
| Will the extracted data be matched against any other registry? |
| If yes, specify registry/registries |
| Authority/registrar |
|  |
|  |
| In which file format would you like the data to be provided? |
| SAS ☐ version \_\_\_  Excel ☐  SPSS ☐ version \_\_\_  Tab-delimited text file ☐  Other ☐ |
| If other, specify which |
| Applicant’s acceptance of terms and conditions of disclosure |
| Date Click here to enter date. |
| The applicant hereby confirms that he/she has read and accepted the terms and conditions for the disclosure of registry data specified below in this document in the decision (**Decision on and terms and decision and conditions for the disclosure of registry data from XXXX registry at the CPUA authority**)  Signature |
| Name (print legibly) Click here to enter text. |
| Enclosures (all enclosures enclosed) |
| * Application for ethical review including enclosures * Decision from Regional Ethical Review Board * Project schedule * Desired variables * If personal data will be processed by someone other than the principal investigator, a written personal data processor agreement must be signed and attached (e.g. if the researcher obtains assistance from external parties for processing data). |
|  |
| |  | | --- | | Decision and terms and conditions for the disclosure of registry data | | Application approved ☐ in accordance with the terms and conditions:   * The disclosed material may only be used for purposes described in the approved ethical review. If the client wishes to use the material for any other purpose, an ethical review must be conducted and approved, and a new disclosure review performed. * Applicable confidentiality stipulations for health and medical care must be followed. * Disclosed materials must be stored in a secure manner to prevent access by unauthorized persons. * If personal data is processed by anyone other than the principal investigator, a written personal data assistant agreement, which also stipulates the terms of use for the material, must be entered between the principal investigator and the other workplace. * Materials may only be published in a way that does not disclose the identity of individuals. * Disclosed materials may only be used as long as is necessary for the specified purpose. The materials must then be archived in accordance with the principal investigator’s rules and regulations. All working copies must be destroyed. * Accurate references to the registry are given in the methodology section and in acknowledgements in the publication(s). * Final report in some form, e.g. scientific article, must be sent to the registry after the project is concluded.   Data will be released with a serial number, but the persons can be identified via a code key held by the registry or by another authority e.g. if registry data from multiple authorities will be matched. Data will be delivered in a secure manner. The extracted data will consist of selections and variables in accordance with the enclosed specification.  The data will be disclosed once the researcher has accepted in writing any special terms or conditions, e.g. costs for the disclosure of data and other services associated with the work specified in a separate enclosure. Alternative formulation: A rate of SEK XXX per hour will be charged for data compilation.    Information on the materials is provided by NN, Phone: XXX-XXXXXX Email: NN@XXXX.XX  The file will be held by the disclosing authority until the project is completed. | | Application denied ☐ | | Reason for denial of application and information on how the decision can be appealed:  Click here to enter text. | |

This document has been prepared in two (2) copies, of which each party has received one.

Name of city 20XX-XX-XX

NN

Registrar, Director or equivalent as delegated by CPUA