



Netherlands Cancer Registry linkage manual

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Amsterdam Cohort Hub

Connecting data, improving health

Background

Registries in the Netherlands contain a wide range of data that can be relevant for the purpose of scientific research. These registry data can be linked on a person-level to the researchers' own data, i.e. cohort, trial or biobank data. To link these two data sources, it is necessary to match key identifying information of participants of your own research data with the registry data. Generally, research on linked data can be performed on an external research environment of the respective registry. However in some cases the registry data can be requested, received and used outside the registry environment. The linkage of data with these registries for scientific research purpose can happen only under certain conditions, that are provided by national legislation and specific laws.

1. OBJECTIVE

This manual provides step-by-step guidance for researchers on linking cohort study data with the Netherlands Cancer Registry (NCR), ensuring compliance with legal, ethical, and technical requirements. It integrates official NCR procedures for data linkage.

2. LINKING WITH NCR

The NCR has been the national source of cancer data since 1989, providing comprehensive and reliable statistics on cancer in the Netherlands. The registry is maintained by the Netherlands Comprehensive Cancer Organisation (IKNL). IKNL is the quality institute for oncological and palliative research and practice. IKNL collaborates with healthcare professionals and managers and patients on the continuous improvement of oncological and palliative care. With data from the NCR, IKNL enables health care professionals, policy makers and others to reflect on cancer care and prevention.

IKNL may only provide data from the NCR if it is used for scientific research or statistics (e.g. epidemiology). Data from the NCR provides insight into trends and patterns regarding the diagnosis, treatment, and survival of cancer. By linking this data to other data sources (cohort studies), many more research questions can be addressed.

2.1. BACKGROUND NCR DATA

The Netherlands Cancer Registry comprises information on newly diagnosed cancer patients in the Netherlands, including cancer diagnosis, tumour staging (according to the TNM-classification developed and maintained by the Union for International Cancer Control (UICC)), tumour site (topography) and morphology (histology) (according to the WHO International Classification of Diseases for Oncology (ICD-O-3)), co-morbidity at diagnosis and treatment received directly after diagnosis.

The available information varies by tumor type. Please consult the NCR data catalogue [IKNL-datacatalogus](#) (Dutch) and the Overview of NCR item sets [Itemsets](#) (Dutch) in advance to see which data are available.

3. PROCEDURAL STEPS

Step 1. Informed consent

The linking of data from the NCR is always carried out under strict privacy conditions. According to the GDPR, organizations may only process personal data when there is a legal basis for doing so. For data linkages, this is typically patient consent (informed consent). As the researcher and project leader, it is your responsibility to ensure you have proper informed consent from your participants or patients that must explicitly allow the linkage between their data with NCR data. If you are unsure whether the consent meets the requirements, consult the privacy officer (via the [Serviceportal](#)) for clarification.

NB. Exceptions may arise. For example, when a cohort is based on the 'no objection' principle. Consultation with the privacy officer, METC and a jurist from NCR is needed.

Step 2. Data Request

As an applicant¹ you can submit a data request ([Gegevensaanvraag](#)). At the end of this document you find a detailed description on how to fill out the request form. IKNL and the project leader/research leader who is also authorized to sign agree on the exact content of the request. These agreements are signed by both parties.

Collaboration Agreement

For every data linkage, IKNL draws up an agreement with all parties involved. IKNL already has a continuous collaboration agreement in place with some organizations. During the processing of your application, IKNL will inform you about which agreement is required.

Costs

Standard data requests for NCR data are provided free of charge. IKNL may charge costs for:

- Data linkage with third parties (such as CBS [Statistics Netherlands] and PALGA)².
- Additional operations (data transformation, formatting, visualization) or research activities.
- Registration of additional items and variables.

IKNL will make a quotation for any paid activities that has to be signed by the applicant.

After agreeing to the quotation, IKNL will retrieve, transform and format the data and set up a data dictionary.

Step 3. Research data and linkage variables

You prepare a file containing the personal data of the selected patients from your cohort. This file must meet a number of minimum requirements. See the instructions for submitting data for details (<https://iknl.nl/getmedia/635ef340-97a1-48c1-8fba-94a7c022a95a/Instructie-aanvrager-format-koppeling.pdf>).

Key variables

For a successful linkage, both the cohort and the NCR must contain variables that can be used for matching, known as "keys". The probabilistic linkage takes place based on a combination of different keys, such as date of birth and sex. The rarer the combination of keys, the more reliable the linkage. The quality of the provided data plays a significant role in this process.

¹ As a researcher, you can complete the form even if you are not the project leader and do not have signatory authority. In that case, you must provide the details of the person who does have signatory authority.

² Linkage with Other Data Sources: NCR also provides the opportunity to link your cohort data to one or more other data sources (e.g. CBS, PALGA, etc.). To do so, you must submit a request to both IKNL and the other organization(s).

Necessary data for linkage

Personal data (such as birth name, sex, date of birth, and postal code) are required to perform the linkage with sufficient certainty.

Mandatory items for linkage:

- Identification number (unique ID of the person)
- Date of birth
- Sex
- Birth name (Surname/Maiden name)
- Birth name prefix (e.g., "van de", "de", "van")
- Initial(s)
- Postcode digits
- Postcode letters

Recommended items:

- Partner's name
- Partner's name prefixes
- Place of birth
- Date of death
- Hospital
- Hospital registration number (medical record number)

If relevant:

- Date of tumor diagnosis
- Screening date
- Date of examination
- Date of treatment
- Does the patient have cancer? Yes/No
- Etc.

Your dataset should be formatted in one of the following file types:

- i. CSV (.csv)
- ii. ASCII (.txt)

Step 4. Secure File Exchange

You send the file to IKNL via a secure file exchange, upon request and following the instructions of your IKNL contact person.

Step 5. Linkage with the NCR

IKNL links your file to the NCR based on the provided personal data. Probabilistic methods are used when linking a study cohort. This involves applying probability calculations that account for the rarity of the keys within the Dutch population. This increases the accuracy of the linkage.

Step 6. Data Delivery

Following the linkage, you will receive the requested NCR data for the matched patients. You will receive an email with instructions for downloading the data, allowing you to subsequently add it to your cohort data (using the identification number, i.e., the person's unique ID).

Appendix 1: How to fill out the request form

This checklist helps you prepare your data request. Use it to verify that you have all the necessary information complete before you start your application.

Note: This checklist is a tool and does not replace the online application form.

1. Personal Details (Mandatory)

1.1 Applicant

- The applicant is the point of contact for IKNL and will be granted access to the portal.
- This does not have to be the same person as the authorized signatory.

1.2 Authorized Signatory

Who is authorized to sign the application?

- For requests regarding your own patients: The treating physician or a doctor from the treatment team.
- In other cases: Project leader or research lead.
- Provide: name, job title, mobile number, and professional email address.

2. Background of Data Request (Mandatory)

Only requests for statistics or scientific research are accepted.

2.1 Motivation (max. 250 words)

- Briefly describe the purpose and background of the request.
- Is this a supplement to a previous request with the same research question? If so, provide the application number of that request (you will not need to fill out the remaining sections again).

3. Desired NCR Data (Mandatory)

3.1 Selection

For which patient group do you wish to receive data?

- Consider: years of diagnosis, tumor type (according to ICD-O-3), location, behavior, morphology, stage, sex, age (standard is 18+), national/hospital-level.

3.2 Aggregation Level

- Do you want data per patient or in the form of an aggregated table?
- If requesting a table, please attach an example.

3.3 Variables

Indicate which variables you need to answer your research questions. Be as specific as possible.

- Consult the NCR data catalog ([IKNL-datacatalogus](#)) and item sets ([Itemsets](#)) for this.

Note: For regular requests, no identifiable or commercially sensitive data are provided (such as personal data, hospital-specific data, or exact dates). Intervals are usually possible. Exceptions may apply (such as requests regarding your own patients).

4. Linkage (If Applicable)

- Is a linkage with another data source required? Check the possibilities on the IKNL website ([Koppelen](#)).
- For linkages not described there, we advise contacting gegevensaanvraag@iknl.nl in advance.

5. Additional Information for Scientific Review (If Applicable)

For requests within the framework of scientific research, additional information is required for the scientific review process.

5.1 Research Proposal

Upload this in the application form.

5.2 Rationale (max. 150 words)

- What is the motivation for the research?
- What is already known and what is not? Support this with literature.

5.3 Research Question (max. 100 words)

- Main question and relevant sub-questions.

5.4 Relevance of NCR Data (max. 50 words)

- Why are NCR (Netherlands Cancer Registry) data necessary?