Manual data request form

This manual guides you step by step in completing the request form for datasets in the National Health Data **https://catalogus.healthdata.nl/datasets.** The purpose of this manual is to support data requestors in submitting a correct and efficient request.

Before starting, please ensure that you have the following information available:

- ✅ A Data Management Plan (DMP) containing a clear description of the project for which you are requesting data
- ✅ Information regarding the purpose and methodology of the project
- ✅ Any relevant approvals, such as from an ethics committee

****Important note:** This data request form is a first version. We are interested in your experiences and kindly invite you to provide feedback for future improvements.

Out of scope for this first version:

Aspects that will be addressed in future releases include:

- Possibility to resume the form at a later stage before final submission to the data holder
- Communication center for direct communication between the data requestor and data holder
- Support for submitting a request for multiple datasets within a single request
- Contract management

If you encounter any problems and/or inaccuracies on the website, please inform us immediately so that we can resolve them. You can contact us via **servicedesk@health-ri.nl**.

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Step 1: Information on the data requestor and the request

In this section, you are asked to provide information about yourself and your project that can be shared with the public. Make sure this does not include any confidential information.

1

Are you requesting access to the dataset on behalf of an organization or as an individual?

If other, please specify

If, on behalf of an organization, then which?

If on behalf of an organization, who is the delegated responsible person?

1 In this section of the request form, you are required to indicate whether you are requesting access to the dataset as an individual or on behalf of an organization. Providing this information accurately is essential for the processing of your request.

You must indicate whether you are requesting access to the dataset:

- ✅ On behalf of an organization (legal entity): you are requesting access on behalf of an institution, such as a university, hospital or research institute.
- ✅ As an individual (natural person): You are requesting access for personal research or in an independent capacity.
- ✅ Other: If you request does not fall under the categories above, please specify and provide an explanation.

When submitting a request on behalf of an organization, you must specify who within the organization is responsible for this request. This may, for example, be your Principal Investigator (PI), department head, or project leader. Please provide the name of this person.

Why is this required?
The designated responsible is ultimately responsible for the request and for the use of the dataset within the organization. This ensures transparency and compliance with the appropriate procedures.

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2

First name of the data requestor

Last name of the data requestor

Mobile/telephone number of the data requestor

Email address of the data requestor

2 This section concerns the collection of contact information of the individual requesting the dataset. This information is important to identify the contact person for the data request, enabling timely communication in case of questions or clarifications.

3

Country of the requesting entity

3 This step concerns recording the location of the organization or institution requesting access to the dataset. This information is important for legal and administrative purposes, such as compliance with regulations regarding data exchange and privacy.

For certain datasets, restrictions may apply depending on the country in which the data is requested or used.

4

Title of the requested dataset

Dataset identifier

From which data holder(s) will the data be extracted?

4 The title and identifier of the requested dataset are automatically populated from the National Health Data Catalogue. In the future, the field for the data holder(s) information will also be automatically populated. For now, the information can still be found in the National Health Data Catalogue.

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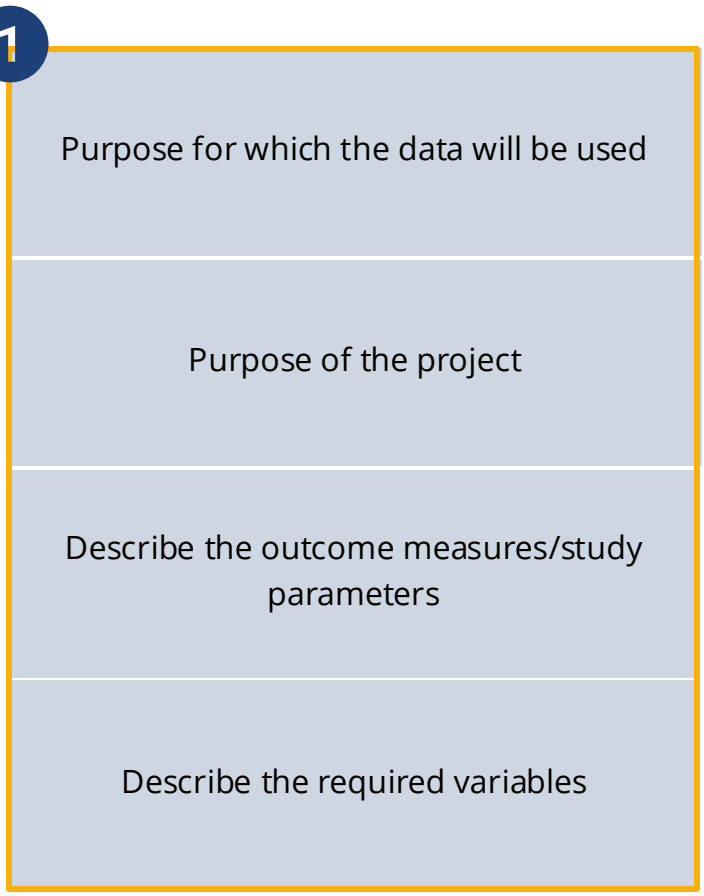
Step 2: Description of the project and dataset needed

In this section, you need to provide a description of the project and the requested dataset, clearly indicating which datasets the application concerns.



1 Here you select the purpose for using the dataset and briefly describe the purpose of the project.

You should also describe the expected outcome(s) and which variables from the dataset are needed to conduct the research.

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Step 2: Description of the project and dataset needed (continuation)

2

The data will be linked to data from other sources

How will the data from different sources be linked?

If you want to link data, you must describe how this will be done. This is a crucial aspect for privacy and security.

Examples:

1. *Personal identification number (e.g. patient ID, study ID)*
   - *Datasets are linked based on a unique number assigned to an individual.*
2. *Encrypted identification codes (e.g. hash function applied to an identification number)*
   - *Personal data is encrypted before being used for linkage.*

2

This step focuses on linking data from different sources and the level of privacy protection of the requested data. This is important for data protection and compliance with privacy regulations, such as the GDPR.

Here, you indicate whether you want to combine the dataset with data from other sources. This is relevant if you need data from multiple sources to answer your research questions.

Examples of data linkage:

- *Linking patient data to genetic information from a biobank.*
- *Linking medical records to socioeconomic data from a population registry.*
- *Combining sensor data (e.g. from wearables) with clinical data.*

3

Do you request anonymous data or pseudonymous data?

3

What should you fill in?

- Anonymous data, if you do not need any identifying information and re-identification is impossible.
- Pseudonymous data, if you need data that can still be indirectly traced back to an individual, but an additional key is required to reveal the identity. The data requestor will not receive this key.

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Step 3: Approval, Plan and Statements

In this section, you are asked to provide information about the various documents required for processing the request.

1

Has a (medical) ethical review been conducted?
Has the study's review been approved in accordance with the non-WMO assessment framework?
Do you have a non-WMO declaration?

1 The non-WMO statement indicates that a study does not fall under the Medical Research Involving Human Subjects Act (WMO).

What should you do?
"Yes" → If required, this will be requested via email. In the future, you can attach it directly.
"No" → The request will be discussed with the data holder.

2

Do you have a Research Proposal Plan that outlines the overview of the research project?
Size of the study cohort Inclusion and exclusion criteria: description of data subjects
For which time period(s) will the datasets be extracted?

2 Do you already have a Research Proposal Plan?

"Yes" → If required, this will be requested via email. In the future, you can attach it directly.
"No" → The request will be discussed with the data holder.

- Size of the study cohort: How many people are included in the study=
- Inclusion- and exclusion criteria: Which participants are included and excluded?
- Time period during which the dataset will be extracted for the project.

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Step 3: Approval, Plan and Statements (continuation)

3

Do you have a Data Management Plan (DMP)?

Project name

Summary of the project

Design/methods of the project

Please select when the project is expected to start

Please select when the project is expected to be finished

3 The Data Management Plan (DMP) describes how data is collected, stored, shared, and protected .

What should you do? Do you have a DMP?
“Yes" → May be requested via email.

"No"→ fill in the following additional information, such as:

- Project name
- Summary of the project
- Design/methods
- Expected project start date
- Expected project end date

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Step 4: Confirmation

In this section, you are asked to confirm the information you filled for requesting the dataset.

1 I confirm that the information I have provided is correct

1 In this section you are asked to confirm the information you have provided before submitting the request.

- Review all details carefully – Ensure all fields have been correctly filled in.
- Review for completeness – An incomplete request can lead to delays or rejection.
- Confirm accuracy of the information provided – This is a formal step where you declare that the information provided is truthful.

What happens after submission and confirmation?

✅ Your request will be reviewed for completeness by the Health-RI case owner and sent to the data holder for review.

✅ Once approved, you will receive an email detailing the necessary follow-up steps.

✅ The data holder can contact you via email when they have further questions and/or requirements.

Questions or issues? Please contact us via **servicedesk@health-ri.nl.**