



Data Access Policy

Policy and conditions for access to data



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1. Introduction

HartslagNu is the Dutch national alarming system for resuscitation. Data is collected of each call for resuscitation, such as date, time and distance of the citizen responder to the victim. HartslagNu makes these data available for scientific research to contribute to the quality of resuscitation care in The Netherlands. This Data Access Policy describes the framework and practical procedures to guide access to and use of data. This policy is a binding document for applicants, who are seeking access to data from HartslagNu.

2. Definitions

Applicant

A qualified person requesting data.

Data

The data collected by HartslagNu in the context of a resuscitation alarm.

Data Access Committee (DAC)

An independent scientific committee with the mandate to review all applications for access to data from HartslagNu. The composition of the DAC is specified in section 8.

Data Transfer Agreement (DTA)

A contract between the Applicant and HartslagNu specifying conditions under which data are transferred to the Applicant.

Provider

HartslagNu provides the data to an Applicant, the execution of the data delivery is delegated to Stan. HartslagNu is a foundation in which the Dutch Heart Foundation, Axira ambulancezorg and het Witte kruis are represented. All 112-control rooms are connected to HartslagNu. Stan provides the technology for alarming citizen responders automatically. Stan also takes care of data management for HartslagNu.

Metadata

All data describing and documenting the HartslagNu dataset, which is necessary for researchers to interpret the dataset correctly.



3. Ethical principles

When data is provided the Applicant and Provider commit themselves to the following principles:

- **Scientific integrity:** Applicant and Provider of the data are expected to act in an honest and transparent manner and uphold the highest standards of quality in scientific research. Requests need to contribute to the objective 'improving the outcomes of cardiac arrest victims'.
- **Responsibility and accountability:** It is both the Applicants' and Providers' responsibility to ensure that both parties have read and understood the relevant policies and procedures. And that both parties act in accordance with them. The Applicant and Provider are aware of the **Algemene voorwaarden** and the **Privacyverklaring** of HartslagNu and act within the boundaries of the permissions given by the citizen responders.
- **FAIR data management:** The Provider takes care of sufficient metadata, to enable the Applicant to interpret the dataset correctly.
- **Open Access publishing:** The Applicant is considered to publish the results of his research with the HartslagNu dataset open access, to increase the accessibility of the results.
- **Respect for responsible governance regarding data and research:** Applicant and the Provider are expected to take the necessary precautions and safeguards to avoid data breaches. This entails protecting their data and putting in place state-of-the-art safety measures for data security.
- **Data Transfer Agreement (DTA):** Before data is handed over, a DTA between the Applicant and Provider is composed. During the research project the Applicant adheres to the conditions stated in the DTA. The DTA will be provided by the Provider.
- **Respect for intellectual property:** Sharing of data needs to be performed in a way that protects intellectual property rights of the parties involved. It also needs to address the requirements of the Applicant's institute and third-party funders.
- **Equity and inclusivity of users:** Researchers who meet the relevant criteria should be granted access, based on fair and non-discriminatory terms.
- **Confidentiality:** The Provider shall treat all the access requests confidentially and will not use them for any purpose other than assessing the availability of the data and access provisions.



4. Request procedure for access to data

An Applicant can submit a request through the following steps:

Step 1: Fill in the request form

- Check whether a request for the desired data set already exists.
- Download the **request form** from the website, fill it out and send it to datahartslagnu@hartstichting.nl.
- Clearly state which variables you wish to receive, which period the data set should concern, and which selection criteria should be applied.

Step 2: Assessment by Data Access Commissie (DAC)

- The request form will be assessed by the DAC, within 8 weeks you'll receive notice of the assessment.
- The request will be assessed on affiliation, funding source, rationale/background, research question, hypothesis, methodology, involvement of other disciplines and possibly social impact and implementation. There will also be a check whether a similar application has been done before (to avoid overlap of analyses) and whether the HartslagNu data set is suitable for answering the research question.
- Data sets are only released for scientific purposes and not for commercial purposes.

Step 3: Feedback from the DAC

- When the request is approved, an invoice and DTA will be sent.

Step 4: Provide data

- After signing the DTA the dataset will be delivered.
- A one-time data set can be provided, or the data set can be periodically refreshed.
- In case of a periodic data set, it will be evaluated at least annually whether data release will be continued.
- The data can be sent in two ways:
 1. The Provider places the data in a safe place where the Applicant can download it.
 2. The Provider sends the data to the Applicant through a secure connection.It differs per request which of these options will be used and depends on the wishes and possibilities of the Applicant.

Step 5: Feedback to HartslagNu

- The Applicant reports the scripts/syntaxes of the analyses, the results and the manuscript to HartslagNu.
- HartslagNu does not require co-authorship, but requests to mention the use of HartslagNu data in the Acknowledgements of the manuscript.



5. Costs

The costs may vary and the amount depends on the financiers.

- € 840 for projects which are (partially) funded by one of the HartslagNu partners The Dutch Heart Foundation or Ambulance Care in the Netherlands.
- € 925 for projects of a public institution with a public funder.
- € 1,680 for projects of a public institution with partial private funders, whereby the results are published publicly. When a request is approved the costs will be determined.

All prices are ex VAT.

6. Publication and Authorship

- Publications based on data delivery from HartslagNu will be in accordance with international recognized scientific and ethical standards concerning publications and authorship, including the Uniform Requirements of Manuscripts Submitted to Biomedical Journals, established by the International Committee of Medical Journal Editors. Copyrights concerning the publications remain with the authors of the publication, regardless of any other provisions regarding intellectual property rights.
- Three months after accessing the data set the Applicant will be asked to provide an update to the DAC. The aim is to finalize analysis and publication within six months.
- For each publication resulting from HartslagNu data:
 - The DAC must approve the manuscript before publication to assess whether the manuscript answers the intended research question (refer to step 5 in paragraph 'Request procedure for access to data'),
 - HartslagNu will be mentioned in the Acknowledgements.

7. Open Access

HartslagNu finds it important that research results are accessible to anyone, both to researchers as to patients, companies and social institutions. Therefore, publications based on HartslagNu data should be published open access. For more information go to the [website of the Dutch Heart Foundation](#).



8. Composition of the Data Access Committee (DAC)

The DAC consists of representatives of the following organizations:

- **Independent chair:** *Arend Mosterd, cardiologist, researcher and chair of the scientific board of the Dutch Heart foundation.*
- **Representative of the Dutch Heart Foundation:** *Paul Huguenin, teammanager Acute Care.*
- **Content expert (with regard to the data set):** *Tom Kooy, business development at Stan.*
- **Respresentative of Ambulance Care Netherlands:** *Bert Dercksen, anesthesiologist en medical manager Ambulance Care at UMCG Groningen.*
- **Representative of the Dutch Resuscitation Council (NRR):** *Marc Brouwer, cardiologist, researcher and member of the scientific council of the Dutch Resuscitation Council.*
- **Coordinator:** *Amanda van der Pijl, Project Coordinator at the Dutch Heart Foundation (no vote in assessment).*