

**Julius General Practitioners Network and Leidsche Rijn Healthcareproject
(JGPN-LRHP)**

Conditions for use of JGPN data

Project number	
Title of research	
Date	

Dear researcher,

You will receive the data from the JGPN-routine-care database from the Data Management department for the abovementioned (by JGPN-LRHP committee approved) application.

The JHN-routine-care database contains data that has been collected over many years and we encourage its use. Simultaneously, we expect that the data will be used with care. There are a number of conditions to which you must comply in order to be allowed to use the data. If you cannot comply to said conditions, the JGPN-LRHP committee has the right to withdraw the permission to use the data.

As part of the general data protection regulation (AVG) statistic data may be generated for research, if pseudonomized files are used and data are not retraceable to individuals.

The data are provided under the following conditions.

General

1. The researcher is responsible for registering at the METC. For researchers of the Julius Center (UMC Utrecht) this means that the [steps](#) have been followed.
2. For research that is not WMO-liable, the researcher is responsible to request a non-WMO-liable statement from the METC. For this the abovementioned steps can be consulted. To ensure a smooth process a quality assurance officer of the Julius Center can be consulted.
3. When data is used from multiple sources (e.g. hospital, GP and/or other (healthcare) parties), the researcher declares that all parties have approved the research application.

Data

1. The obtained data may only be used to answer the research question
2. After the committee gives their approval there will be a meeting about the data between the executing researcher, their supervisor and the data manager. During this meeting the following aspects will be discussed in detail:
 - a. Which data is requested.

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- b. How these data can and will be delivered. For the data manager it is important to know how the data will be analyzed and presented in the final results. Showing empty result tables can be helpful.
 - c. When the data can be expected. The researcher is expected to reserve a sufficient amount of time to successfully execute data-analyses within the discussed timeframe. In case this is not possible, a new timeframe will be determined.
3. Before delivering the agreed data you will receive a quotation. Only after signing this quotation will the data be delivered.
4. When you receive the data you will be asked to sign and return the confidentiality agreement of the JGPN.
5. The data are only made available in a Digital Research Environment (DRE). Within the DRE you will have access to the agreed data and can perform the analyses needed to answer your research questions. In case JGPN-data will be linked to data of the CBS, a personal CBS-environment must be requested. It is not allowed to place multiple datasets from different JGPN-requests in the same CBS-environment.
6. The data are delivered for the duration of the research. After completion of the research the researcher is expected to return the received data to the JGPN, including added variables (calculations, adaptations, additional deliveries). Any copies must be destroyed by the researcher. JGPN will save the data for reuse, if applicable.
7. Received data of JGPN, including raw data and the final dataset that was used for analyses, can never be made available for "Open Access". However, research can request data at JGPN if desired. Making metadata available is allowed. If a journal desires publishing raw data, the following can be communicated: *"All relevant summary data are provided in the paper and its supplemental information. The committee of the network of general practices in which our study was conducted, is the formal owner of the research data ('The Julius General Practitioners' Network, JGPN, [Julius Huisartsen Netwerk - UMC Utrecht](#)). Unfortunately, the raw data cannot be made publicly available due to ethical and legal restrictions. The de-identified data are traceable to the participating centers (through the number of participating patients) which did not explicitly approve of raw data publication. However, all interested readers may request data without restriction from the JGPN board (secretariaatJHN-3@umcutrecht.nl)."*
8. The committee reserves the right to add a (GP-)researcher to the research group of estimated that this person can provide a meaningful addition. In this case this person must be actively included in the analyses and preparation of the manuscript.

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Publication

8. Prior to publication:

You are expected to always offer the manuscript to the daily management of JGPN at least 2 weeks *before* submitting the manuscript to a journal. An abstract for a congress must be offered at least 1 week *before* submission. The daily management of JGPN reserves the right to suggest adaptations in the manuscript if the description of the database, as described below, is insufficient or if the interest of the database is violated.

9. Upon publication:

Upon publication the JGPN expects **correct reference to the JGPN** and correct description of how the data were obtained. The following guidelines apply:

- Abstract, methods:

'We performed a study using the routine health care database of the Julius General Practitioners' Network'

- Article, methods:

"Data were obtained from the Julius General Practitioners' Network (JGPN) database, which contains routine health care data anonymously extracted from electronic primary care settings in the area of Utrecht (ref).*

*Smeets HM, Kortekaas MF, Rutten FH, Bots ML, van der Kraan W, Daggelders G, Smits-Pelser H, Helsper CW, Hoes AW, de Wit NJ. Routine primary care data for scientific research, quality of care programs and educational purposes: the Julius General Practitioners' Network (JGPN). BMC Health Serv Res. 2018Sep25;18(1):735. doi: 10.1186/s12913-018-3528-5. PubMed PMID: 30253760; PubMed Central PMCID:PMC6156960.

- After publication:

After publication the committee wishes to receive an electronic version of the article including a short summary of the article in Dutch. The Dutch summary is transcribed into an easily understandable text so laymen may understand the research and results. The summary will be published on the website of JGPN. Additionally, a link to the article will be published on the website.

Progress reports

11. Every six months the researcher will receive a progress form through which the researcher will report in short about the current state of the research and the expectations about the finalization of the research.

Finances

12. After receiving the data you will receive an invoice. The invoice will be sent to the researcher who has received the data as well as to the administrative responsible of the research. The invoice corresponds to the sum as mentioned in the signed quotation.

We would like to receive your agreement to the above conditions. You can send these to: secretariaatJHN-3@umcutrecht.nl

Name researcher

Date

Signature
July 2022