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Data Resource Profile

Data Resource Profile: Registry of electronic health records of general practices in the north of The Netherlands (AHON)

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Key Features

- The AHON registry contains longitudinal data from the electronic health records (EHRs) of 73 general practices in the north of The Netherlands. Established in 2017 by the Department of Primary and Long-term Care at the University Medical Center Groningen, using data from 2013 onwards, data are collected by quarterly imports from EHRs.
- The registry contains information about 460 795 patients, with a median (interquartile range) follow-up of 5.5 (3.0–7.6) years, at both the practice level (e.g. location and practice size) and the patient level (e.g. demographic, episode based, and other medical information). It contained 306 242 active patients on 1 July 2022.
- The infrastructure is mapped onto a common data model to enable collaboration with other general practice registries.
- To date, the AHON registry has been used in many studies. It is well suited for joining with other data sources both vertically (adding new variables) and horizontally (adding other external population registry files).
- Researchers interested in collaboration can contact the AHON team at [AHON@umcg.nl].

Data resource basics

Background

In The Netherlands, health care is based on the principles of accessibility, solidarity and quality.¹ Accessibility is facilitated through a local general practitioner (GP) who not only acts as a gatekeeper for secondary care referrals but also manages a wide variety of acute and chronic health issues in primary care. Solidarity is ensured by health insurance that covers 99% of the Dutch population.² Quality is maintained by GPs using and creating evidence-based guidelines and by them structuring their electronic health records (EHRs) based on International Classification of Primary Care codes. This approach to health care ensures that patients receive consistent care and oversight in the long term.

The AHON registry

Longitudinally collected data in primary care EHRs have great research potential. Therefore, the University Medical Center Groningen established and developed a research registry using

Dutch EHR data. Starting with three practices as the Registration Network Groningen in 1989,³ this later expanded in 2017 to become the Academic General Practitioner Network (AHON, Dutch: Academisch Huisartsen Ontwikkel Netwerk) governing the AHON registry.⁴

The AHON registry contains the routinely collected and pseudonymized data for 73 affiliated GP practices in the north of The Netherlands since 2013. GP practices become affiliated with all their GPs at their own request. Patients registered at an affiliated practice are automatically included in the registry unless they choose to opt out (0.2%). As of the 1 July 2022, the registry contained the EHR data of 460 795 patients with a median follow-up of 5.5 years (IQR: 3.0–7.6) years. [Figure 1](#) shows the geographical distribution of patients in the registry. The registry currently includes 306 242 active patients, accounting for 10.5% of the population in the north ([Table 1](#)). Over half of the patients in the registry live in non-urban or hardly urban areas, with only 6.0% residing in extremely urban areas (defined as ≥ 2500 addresses/km²).⁵ The AHON registry provides in-depth information for both GP practices (e.g. location

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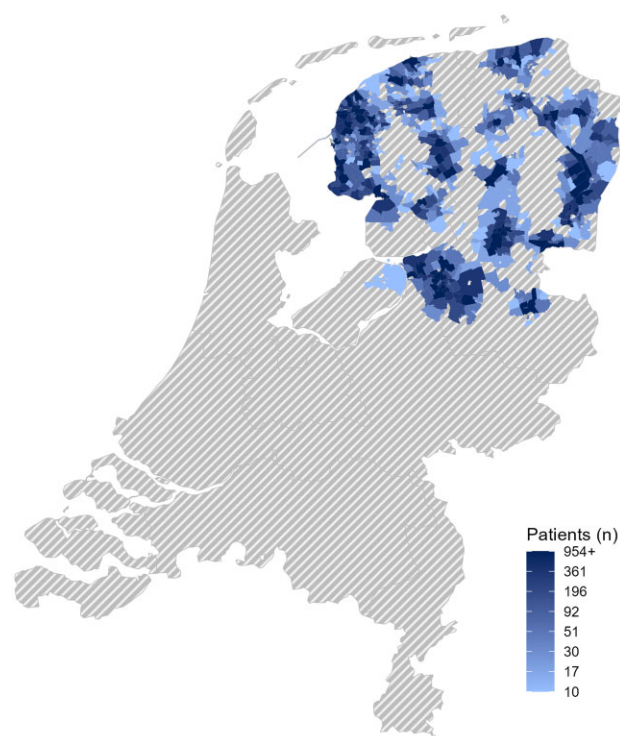


Figure 1. Active population by postal code (PC4) in the AHON Registry. To preserve privacy, only areas with ≥ 10 patients are included. AHON: Academic General Practitioner Development Network (Dutch: *Academisch Huisartsen Ontwikkel Netwerk*)

Table 1. Demographic characteristics of the AHON Registry.

Characteristic	All patients ^a	1 July 2022 ^b
Total number	460 795	306 242
Sex		
Male	228 581 (49.6%)	153 276 (50.1%)
Female	232 214 (50.4%)	152 966 (49.9%)
Age (years)		
<5		13 963 (4.6%)
5–17		43 453 (14.2%)
18–64		180 090 (58.8%)
>64		68 736 (22.4%)
Province		
Drenthe		76 073 (24.8%)
Friesland		108 082 (35.3%)
Groningen		42 204 (13.8%)
Overijssel		79 883 (26.1%)
Urbanization ^c		
Extremely		18 382 (6.0%)
Strongly		35 723 (11.7%)
Moderately		61 232 (20.0%)
Hardly		80 088 (26.1%)
Not urban		110 475 (36.1%)
Follow-up in years, median (IQR)	5.5 (3.0–7.6)	6.9 (4.2–8.3)

^a All patients: total number of patients present in the registry. AHON, Academic General Practitioner Development Network (Dutch: *Academisch Huisartsen Ontwikkel Netwerk*); CBS, Statistics Netherlands (Dutch: *Centraal Bureau voor de Statistiek*); IQR, interquartile range.

^b Active patients: alive, currently (1 July 2022) registered patients in the registry.

^c Using CBS microdata urbanization classification⁵ based on postal code. For part of the population ($n = 342$), urbanization is unknown due to an unknown postal code or their postal code not being classified by CBS.

and practice size) and patients (e.g. demographic, episode based and other medical information). Figure 2 shows the number of active patients in the AHON registry over time.

The registry is updated with quarterly imports from the EHRs of affiliated GP practices. These provide updates on the health care received by the population, plus any (de-) registrations, resulting in a dynamic population. The structure of the registry also makes it suitable for linking with GP cohorts from other regions of The Netherlands using the same structure, thereby expanding the research scope to a larger population. It is also possible to enrich the current population by incorporating new variables.

Ethical clearance and privacy measures

Affiliated practices are required to inform patients about the use of their data for research purposes, and the AHON team supplies materials for this purpose. To comply with Dutch legislation, patients can opt out of participating at any time. At this point, their names will be put on a refusal list, their data removed from the registry and their data no longer extracted in future collections. To preserve privacy, a trusted third party⁶ creates pseudonyms as patient identifiers, and internal software⁷ anonymizes free text notes in the registry.

Funding and follow-up

Researchers analysing AHON data pay a fee that covers the maintenance of the registry, virtual research environments and any support by the AHON team. Additionally, the registry benefits from basic research funding provided by the Dutch Federation of Academic Hospitals (Dutch: *Nederlandse Federatie van Universitair Medische Centra*), as it is one of seven core longitudinal cohorts in the University Medical Center Groningen.⁸ The registry is intended to collect routine data indefinitely.

Data collected

Data process from source to registry

Quarterly imports from the EHRs of affiliated GP practices update the registry. To ensure data protection and privacy, a trusted third party pseudonymizes patient identifiers and transfers the data. These pseudonyms are constructed using mixed combinations of key variables. The AHON registry can provide in-depth information at the levels of both the GP practice and the patient. The practice level includes information about practice location, size and the type of co-workers (e.g. GP, assistant, nurse). The patient level includes demographic information (e.g. birth date, locality, sex), episode-based information (e.g. contacts, actions and GP notes) and other medical information not based on a specific episode (e.g. medications, allergies and contraindications).

Data types

The AHON registry, similar to many GP registries, stores structured and categorized data about symptoms and diseases (using International Classification of Primary Care codes), medications (using Anatomic Therapeutic Chemical) and insurance claim codes. However, it also contains data from unstructured text fields, such as the anonymized GP notes in SOAP format (Subjective, Objective, Assessment, and Plan), but it does not include imaging data, such as photos, ultrasounds and scanned

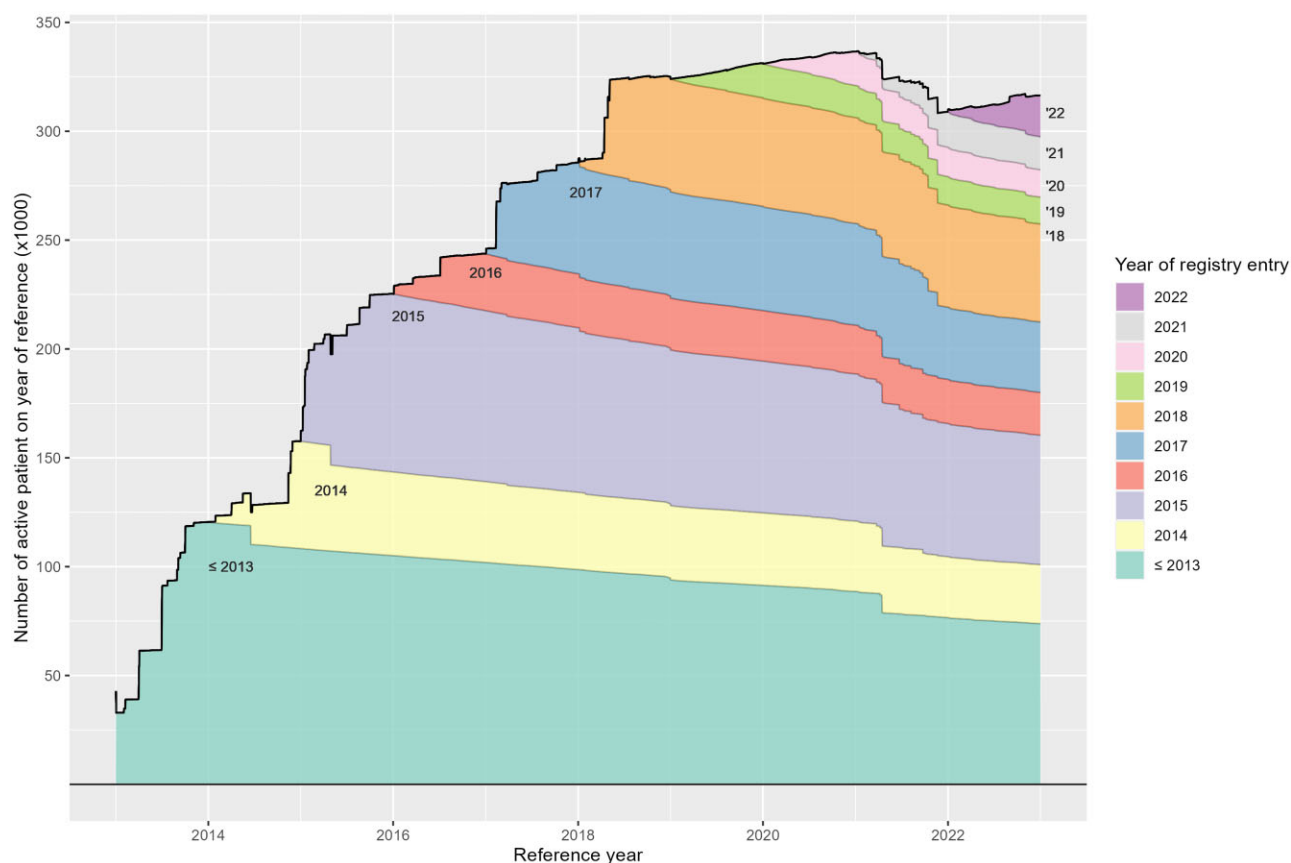


Figure 2. Total AHON registry population by year of entry. Data from before 2013 originate from the Registration Network Groningen database and are included in the AHON registry (note that this source may not be complete). The figure shows the number of patients for each reference year with their year of first occurrence in the registry, illustrating their follow-up. For example, when looking at the population for the reference year 2019, about 200 000 patients had been followed up since at least 2015. Newly affiliated practices extract data for the prior 5 years, meaning that practice inclusion of in 2017 led to population growth in 2013, and practice inclusion in 2022 led to population growth from 2018 onwards

Table 2. Type of data collected in the AHON Registry.

Data	Contents	Description
Demographic		
Practice	Locality, size, co-workers, EHR	AGB
Patient	Date of birth,* date of death,* locality, sex, (de)registration date, category	*month-year
Episode-based information		
GP note entry	GP note, SOAP structure	ICPC-1
GP note	Contact, diagnosis, episode	ICPC-1
Actions	Contact, description, type, rate	
Contacts	Episode, date, duration, type, co-worker	NHG Table 14
Episodes	Date, type, status, description, co-worker	ICPC-1
Other medical information		
Measurements	Episode, reason, type, result, material	NHG Table 45
Medications	Episode, type, indication, duration, dose, quantity, instructions, administration method	ATC, Z-index
Contraindications	Episode, administration method, description	Z-index
Allergies	Date, product, group, administration method	Z-index
Referrals	Episode, specialism, free text, referral institute	NHG Table 12

AGB, Dutch health care provider coding (Dutch: Algemeen GegevensBeheer); AHON, Academic General Practitioner Development Network (Dutch: Academisch Huisartsen Ontwikkel Network); ATC, Anatomical Therapeutic Chemical coding; EHR, electronic health records; ICPC-1, International Classification of Primary Care; NHG, Dutch GP Association (Dutch: Nederland Huisarts Genootschap); NHG Table 12, Third party coding; NHG Table 45, Diagnostic measurement coding; NHG Table 14, Contact type coding; SOAP, Subjective, Objective, Assessment and Plan; Z-index, index of available Dutch health care products.

PDFs. The full structure of the AHON registry can be found in [Table 2](#), which details the data available at each level: practice (e.g. demographics) and patient (i.e. demographic, episode-based and other medical information).

Data quality measures

Qualitative and quantitative checks are performed before importing data into the AHON registry. Qualitative checks include verifying names and formats (i.e. file, table and variable),

ensuring the completeness of key tables (i.e. GP note entries and actions) and confirming that the EHR software has remained the same since the previous import. Quantitative checks include comparing the total number of patients, and their identifiers, with the previous import, before flagging any discrepancies as suspicious and requiring manual examination. Data are then allowed into the registry and corrected or removed based on the adequacy of the resulting explanation. Before preparing research datasets, the following preliminary checks may be performed: the total number of GP practices and patients, patient (de-)registration dates within a practice, distributions of numerical and categorical variables, time trends and duplicates in rows and/or columns. Quality measures at this stage will depend on the research question, ensuring that only necessary data are included to comply with the European General Data Protection Regulation. Apart from these measures, the data are left as unprocessed as possible. Guidelines and custom statistical tools are provided to the researcher. The final decisions on handling missing data are the responsibility of the researcher, to whom this relative unprocessed data are provided. Data from different practices within the registry are not linked; when a patient leaves the GP practice for another practice, their follow-up will end. If the new practice for that patient is also affiliated, they will be registered as a new patient. When doing longitudinal research these patients can, at the researchers' request, be tracked via their pseudonyms.

Representativeness

The age and gender distributions of the registry population are comparable to regional norms in the north, such that the populations aged <18 years and >65 years are slightly over-represented compared with the general Dutch population. The AHON registry contains a relatively large proportion of individuals from less urban areas compared with national and regional data. Specifically, the registry contains a higher percentage of individuals from non-urban to moderately urban areas (82.2%) compared with the national percentage (50.5%). When compared against the weighted average in the north of The Netherlands, the AHON registry contains a higher percentage of individuals from less urban areas (82.2% vs 76.0%).⁹ Researchers should take this into account when using AHON data to answer descriptive research questions.

Linkages

External data are not linked by default when collecting data, although the registry structure is designed to enable linkage with other registry or cohort data in two ways.

First, the registry uses a common data model (CDM) designed in collaboration with University Medical Center Utrecht and Amsterdam Medical Center (Vrije Universiteit location), to harmonize the data, promote collaborative research and facilitate horizontal linkage with other registries (i.e. adding similar populations). Amsterdam Medical Center and Maastricht University Medical Center joined later and harmonized their registries to the same CDM. In ongoing and published studies, we have successfully linked our registry with other GP networks based on different data models, including Radboud University Medical Center and the Nivel Primary Care Database.¹⁰ Furthermore, we can also use the Observational Medical Outcomes Partnership (OMOP) CDM, which is widely used for clinical data.¹¹ Although the OMOP CDM is more distilled than the CDM on which the

AHON registry is mapped, it offers opportunities for international collaboration. Therefore, the AHON registry is structured using its original CDM to keep the full extent of the data available, but it is also possible to extract OMOP-formatted datasets to facilitate international collaboration. The experienced AHON team can assist with this process.

Second, standardized pseudonyms are available through a trusted third party,⁶ enabling vertical linkage with other parties (i.e. adding new variables to the population). This provides the opportunity to deliver customized datasets enriched for specific research questions. In previous studies, we have enriched datasets from our population with data from several sources, including the Netherlands Comprehensive Cancer Organisation (Dutch: Integraal Kankercentrum Nederland),¹² Statistics Netherlands (Dutch: Centraal Bureau voor de Statistiek),¹³ Public Health Service Groningen (Dutch: Gemeentelijke Gezondheidsdienst),¹⁴ and Certe, a primary and secondary care diagnostics centre.¹⁵

Data resource use

Studies using the AHON registry

Before 2017, when the AHON registry took on its current form, 44 studies had been published in peer-reviewed journals based on Registration Network Groningen datasets. Since 2017, there have been four publications in international peer-reviewed scientific journals. These considered primary care diagnostic and treatment pathways in Dutch women with urinary incontinence,¹⁶ psychosocial problems and contraceptive use in woman with unwanted pregnancies,¹⁷ the impact of the COVID pandemic on cancer-related symptoms¹⁸ and psychotropic drug prescriptions for older people with dementia.¹⁹ Another 43 AHON projects are also in progress to examine health care usage, COVID-19, oncology, depression and cardiovascular risk management, prevalence and management of Dupuytren's contracture, pelvic floor problems, pharmacology and the applicability of machine learning techniques on EHR data. An exhaustive list of all published Registration Network Groningen and AHON studies, together with the ongoing research, can be requested by contacting [AHON@umcg.nl].

Strengths and weaknesses

Collection process

The continuous quarterly data collection allows for a rising number of records, but the use of pseudonymization blocks the possibilities of going back to the patient for additional data (e.g. questionnaires) and of tracking individual patients across multiple GP practices. However, pseudonymization ensures patient privacy and a ready-to-research registry that does not require additional ethical approval. The voluntary nature of becoming an affiliated GP practice can cause some overlap with other registries, i.e. when a GP practice decides to join multiple registries. In the rare case this does occur and multiple registries are used within the same research, double patients can be found based on their pseudonyms.

Completeness

The comprehensiveness of the collected medical records is another strength. However, the relative rawness of the records means that researchers must first become acquainted with the data before diving into their methodology. By containing the

full longitudinal medical primary care records (EHRs) of the population, including both structured and unstructured data (e.g. free text SOAP notes),²⁰ it is possible to answer a broad range of research questions, including those that use advanced natural language processing techniques.

Suitability for secondary use

EHR data are primarily used and collected for clinical use, whereas in the AHON registry, these are used for secondary research purposes. This is a weakness of most GP registries.²¹ Data collection by GPs in EHRs prioritizes clinical over research use, which may lead to under-reporting of diseases and non-random data collection. This issue risks missing data or causing misclassification, feeding back to the need for researchers to become acquainted with the nature of the available data. Specifically, the nature of missing data and the specific research question need to be considered when using AHON data. Misclassifications always lead to biased results in descriptive studies, and studying associations requires careful consideration of the differential or non-differential nature of any misclassification. In the case of datasets based on AHON data, missing values often result from a non-random mechanism, with imputations often recommended as a solution for handling missing data. However, researchers must consider the potential bias introduced by imputations when data are not missing at random.

Registry structure

The registry structure, by using a CDM, makes it easy to link with other populations or to enrich with data from external sources. To retain as much of the original richness as possible, the CDM is not mapped according to the European OMOP CDM in the first instance. Therefore, linking data with OMOP-based datasets, like the Integrated Primary Care Information database,²² requires more effort. However, linking with OMOP-based datasets has been done before and scripts are being developed to map our CDM to the OMOP CDM, which will allow standardized analysis in projects requiring international collaboration. The support team and data experts at AHON have experience and can provide advice on best practice.

Data resource access

Relevant documentation

A factsheet is available to explore the potential of using the AHON registry in research.⁴ The University Medical Center Groningen Research Data Catalogue contains additional metadata on the registry.²³

How to apply for access and contact details

The research section of the Department of Primary and Long-term Care of the University Medical Center Groningen manages the AHON registry. Researchers from other institutes and affiliated GP practices can submit requests for data from AHON through a standardized data request process. This is overseen by the AHON committee, comprised of affiliated GPs and researchers, which evaluates each data request based on specific criteria (i.e. clinical relevance, quality and methodology). If a request is approved, a data manager will contact the researcher to translate their research question into a request for a specific dataset. The data are then extracted from the registry and provided to the researcher in a virtual

research environment. If required, data scientists from AHON can provide support with data cleaning, analysis and visualization. Proposals for collaborations or studies using the registry can be sent to [AHON@umcg.nl]. Please note that a fee is payable for the use of data from the AHON registry. Other enquiries regarding this paper can be sent to the corresponding author: [r.twickler@umcg.nl].

Ethics approval

The medical ethics committee of UMCG has concluded that the protocol does not constitute clinical research with human subjects, as meant in the Medical Research Involving Human Subjects Act (WMO). This declaration for the AHON registry is recorded in the medical ethics research register of UMCG (no. 202100077) and in the PaNaMa research management system (no. 9694).

Data availability

See 'Data Resource Access', above.

Author contributions

R.T., M.Y.B. and L.L.P. drafted the first concepts of the paper. R.T. and K.S. performed data analysis and prepared the tables and figures. F.G. provided information on data extraction, registry infrastructure and workflow. N.T.S. provided information on application procedures and ethical approval. E.A.B., M.H.B., M.R.B. and C.G.H.B. contributed to the development of the paper. All authors interpreted the results, provided information for the content and critically reviewed and approved the final version of the manuscript.

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Conflicts of interest

None declared.

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