EXPERIENCE REPORT

# Lessons learned from the development of a national registry on dementia care and support based on linked national health and administrative data

Iris van der Heide[1] | Anneke L. Francke[1,2] | Carola Döpp[3] | Marianne Heins[1] | Hein P. J. van Hout[2] | Robert A. Verheij[1,4] | Karlijn J. Joling[2]

[1]Department Healthcare from the Perspective of Patients, Clients and Citizens, Nivel, Netherlands Institute of Health Services Research, Utrecht, The Netherlands

[2]Amsterdam Public Health Research Institute, Amsterdam UMC, VU University Medical Center, Amsterdam, The Netherlands

[3]Rehabilitation Department, Radboudumc, Nijmegen, The Netherlands

[4]Tranzo Scientific Center for Care and Welfare, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands

**Correspondence**
Iris van der Heide, Nivel, Netherlands Institute of Health Services Research, Otterstraat 118 – 124, 3513 CR Utrecht, The Netherlands.
Email: i.vanderheide@nivel.nl

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## Abstract

**Introduction:** This paper provides insight into the development of the Dutch Dementia Care and Support Registry and the lessons that can be learned from it. The aim of this Registry was to contribute to quality improvement in dementia care and support.

**Methods:** This paper describes how the Registry was set up in four stages, reflecting the four FAIR principles: the selection of data sources (Findability); obtaining access to the selected data sources (Accessibility); data linkage (Interoperability); and the reuse of data (Reusability).

**Results:** The linkage of 16 different data sources, including national routine health and administrative data appeared to be technically and legally feasible. The linked data in the Registry offers rich information about (the use of) care for persons with dementia across various healthcare settings, including but not limited to primary care, secondary care, long-term care and medication use, that cannot be obtained from single data sources.

**Conclusions:** A key lesson learned is that in order to reuse the data for quality improvement in practice, it is essential to involve healthcare professionals in setting up the Registry and to guide them in the interpretation of the data.

**KEYWORDS**
data linkage, data reuse, dementia, quality improvement, registry

## 1 | INTRODUCTION

People with dementia often go through a long care process during which they receive care and support from various providers, including for instance care from their general practitioner, home care, day care, hospital care, and long-term care. Virtually all care providers routinely record health and care-related data in electronic files or administrative systems for persons who are under their care. That data can be stored in data repositories. The linkage of routinely recorded health and care data from various repositories makes it possible to identify persons with dementia and to obtain insight into their use and quality of care across different healthcare settings.[1]

Reusing data for quality improvement in practice is one of the key principles of a learning health system.[2,3] The Institute of Medicine in the USA was among the first to address the need for a learning system in the health domain.[3-5] Since then, an increasing number of publications have recognized the importance of learning health systems and the application of big data to improve healthcare delivery,[6-9] including in the field of dementia care.[10,11] In addition, reusing data

sources for research ties in with calls for increased data sharing and using limited resources more efficiently to answer new research questions.[12]

However, the linkage of different data sources can be complex and there are still challenges to overcome with respect to data governance, technical aspects, privacy and confidentiality, funding, data management skills and encouraging stakeholders to share data, as described by the Organisation for Economic Co-operation and Development (OECD).[10] This complexity touches on the 'FAIRness' of data: to be Reusable for quality improvement or research, data needs to be Findable, Accessible and Interoperable.[13] The OECD recommended learning from current and developing practices to tackle these challenges.[10]

Given these complexities, there are currently few countries with a national registry with linked data on characteristics of people with dementia and/or on dementia care. To date, there are only two EU countries with national dementia registries based on routine (health) data: Denmark[14] and Sweden.[15] In Ireland, the development of a national dementia registry based on routine data has been explored, but it is a complex task because of fragmented data from multiple settings that are mostly not standardized and recorded in unconnected systems, which makes retrieval difficult.[16] Some countries, such as Italy, have local dementia registries.[17]

Besides dementia registries, several countries have other national disease specific registries, such as cancer registries in for instance Norway, Finland and the Netherlands[18-20] or diabetes registries in for instance Sweden and Denmark.[21,22] These registries have in common that they use health data of individuals with a specific disease to provide information about quality indicators in care or about the incidence and prevalence of a disease.

In the Netherlands, a new national dementia registry, known as the Dementia Care and Support Registry (referred to hereafter as 'the Registry'), has been developed. This registry is distinct from other disease-specific registries, including the Swedish dementia registry, SveDem, in several key ways. While SveDem, like other disease-specific registries, is based on health data of persons with dementia, the Dutch Registry is based on a broad range of existing and national covering routinely recorded health and census data. This allows in the first place for persons with dementia to be identified based on the data and to provide not only health and care-related information, but also information on their socioeconomic characteristics such as household income and area of residence, as well as the utilization of social support. Furthermore, the administrative burden typically associated with registries that rely on manual data entry can be circumvented by utilizing existing routinely recorded data sources.

The Dutch Registry is most comparable to the Danish dementia registry, which also combines health and census data based on unique personal identification numbers. Yet the Danish registry provides information on dementia incidence and prevalence. The objective of the Dutch Registry, on the other hand, was to provide insight into the background characteristics of people with dementia and their use and the quality of various types of care and support, including long-term care.

The linkage of multiple national covering health and census data sources, containing data on multiple years, leads to a rich data repository that provides researchers with the opportunity to investigate various aspects of dementia care and support, including utilization rates and quality, while also exploring a wide range of social determinants of dementia and inequalities in dementia care and support. In addition, researchers can study care trajectories, trends and changes over time. This makes the Dutch Dementia Care and Support Registry unique in its kind.

The main overall aim of the Registry is to contribute to a learning health system by providing national and regional feedback reports that could be used for quality improvement by policymakers as well as organizations providing care or support to persons with dementia.

## 1.1 | Question of interest

This article aims to provide insight into the development of the Registry and the lessons that can be learned from it, which could be valuable for the development of comparable registries in other countries or for different patient populations.

## 2 | METHODS

## 2.1 | Project team and steering committee

The development trajectory of the Registry, which ran from 2017 to the end of 2020, was financially supported by the Dutch Ministry of Health as part of a broader national dementia quality improvement programme.[23] Researchers and legal experts at the Netherlands Institute for Health Services Research (Nivel) had the main executive tasks in the development of the Registry. To guide the development of the Registry, a steering committee was established that included representatives of Alzheimer Netherlands and the Dutch Ministry of Health, Welfare and Sport.

## 2.2 | Definition of persons with dementia

Together with the steering committee, the project team determined the selection criteria for the identification of persons with dementia based on existing data sources. Table 1 describes the data sources as well as the criteria that were used to identify persons with dementia. This approach is similar to that used by the Danish dementia registry,[14] but is more comprehensive in that it incorporates long-term care data as a source of information, which was not part of the Danish dementia registry. In addition, the project team determined together with the steering committee which data had to be included in the Registry in order to produce feedback reports about the use and quality of care for people with dementia. This decision was made in consultation with healthcare professionals from the approximately 60 dementia care networks in the Netherlands. Dementia care networks are regional networks of collaborating organizations (eg, home care organizations, nursing homes) that provide care to persons with dementia.

**TABLE 1** Criteria used for the identification of persons with dementia in national data sources.

| Persons were identified as having dementia if at least one of the following criteria was met: | Data sources, coverage and years used |
| --- | --- |
| Diagnosis code ICPC P70 (dementia) | Nivel Primary Care Database (ie, nationally representative data from 10% of all Dutch GP practices, on care provided in GP practices and out-of-hours GP services) Data up to and including 2019 |
| ICD 10 diagnosis codes: F00 (Alzheimer's disease) F01 (vascular dementia) F02 (dementia as an aspect of another condition) F03 (unspecified dementia) | National Register of Hospital Care (ie, nationwide data on hospital care from all Dutch hospitals) Data from 2014 up to and including 2019 |
| Medication code (ATC code) N06D (anti-dementia medication) | Medicine prescriptions (ie, nationwide data on dispensations of medicines that are reimbursed under the Dutch basic healthcare insurance, which is mandatory for everyone who lives or works in the Netherlands) Data from 2008 up to and including 2019 |
| Indication for care package ZZP5VV—VV (sheltered housing with intensive dementia care) and/or psychogeriatrics as the predominant reason for an indication under the Long-Term Care Act and/or psychogeriatrics as a secondary reason for an indication under the Long-Term Care Act. | Indications for care under the Long-Term Care Act (ie, nationwide data on indications for all types of long-term care that are provided in the Netherlands, including nursing-home care) Data from 2015 up to and including 2019 |

## 2.3 | Four stages reflecting FAIR principles

This article provides insight into the development of the Registry by describing the four different stages of the developmental process, each of which is related to one of the four FAIR principles: Findability, Accessibility, Interoperability, and Reusability. In the discussion section, the most important lessons learned from each of these four stages will be described.

## 3 | RESULTS

### 3.1 | Stage 1: Selection of data sources

The development of the Registry started by identifying persons with dementia in order to provide insight into their background characteristics

and the use of dementia care and support services. The guiding principle was that only existing data sources should be used, in order to avoid any additional administrative burden for healthcare professionals. Hence various existing relevant data sources were selected that contained national or nationally representative data covering background characteristics and a broad range of care and support options used by people with dementia.

According to the FAIR principles, data should in the first place be Findable, for example, datasets should be described, identified, and recorded or indexed in a clear manner.[13] In this regard, it was helpful that we could base the selection of data sources to a large extent on a previous project that served as a preparation for the development of the Registry. This was the 'BESIDE project' of Joling and colleagues.[1] In the BESIDE project, Joling et al. used various existing data sources, on GP care, hospital care, home care, long-term residential care, and medication prescriptions, to obtain insight into the care trajectories of people with dementia.

In addition to the selection of sources based on the BESIDE project, stakeholder consultations were held in order to obtain a better understanding of their information needs. This included consultations with healthcare professionals working in organizations within dementia care networks. They expressed interest in how the use of dementia care and support options differed depending on the background characteristics of persons with dementia, for instance with respect to their living situation (alone or with a partner) and their region of residence, but also with respect to socio-economic characteristics. Information on these types of background characteristics is available in national population-wide administration databases, stemming from all municipalities and brought together by Statistics Netherlands. Data from these databases was therefore used in the Registry.

However, the FAIR principle that the data should be findable, together with the intention to avoid any extra administrative burden, also meant that the Registry could not meet all information needs. For instance, professionals showed interest in data on dementia case management, but the existing national data sources did not include this kind of data. In addition, during the mapping of national data sources, it became clear that there was a great deal of data available on care use, but very limited data on the quality of this care.

Furthermore, data was available on the dementia diagnoses, but no data on the specific type, stage, or severity of dementia. This type of information is not systematically recorded following standardized procedures. Instead, healthcare providers at hospitals or general practices can enter such information in free text fields. However, these free text fields are not integrated into the Dutch Hospital Data or the Dutch Nivel Primary Care Database because it is not feasible to pseudonymize these free text fields, rendering this type of information currently unavailable for research and registry development. In the development of the Registry, Stage 1—'selection of data sources'—ended with meetings between the project team and data-source processors or administrators to obtain a better understanding of the selected data sources.

## 3.2 | Stage 2: Obtaining access to the selected data sources

The 'A' in the FAIR principles means that datasets should be Accessible through a clearly defined access procedure. The data sources that had been selected for the Registry have various data processors and, except for the data on care provided by GPs, were all made available by Statistics Netherlands, which holds the mandate to give permission for the use of most of the data sources they administer, though often only after the consent of the data source processor. The latter applied to the national database of hospital data. Access to hospital data had to be requested from the Dutch Hospital Data organization. Permission to use data on GP care had to be obtained from Nivel.

The data were requested using the data application forms that were available on the websites of the data source processor or of Statistic Netherlands. The data request contained information on the objectives of the research project, how the requested data could contribute to these objectives and the legal grounds for the data request. The data request applications that were submitted to Statistic Netherlands, Nivel and Dutch Hospital Data were internally reviewed by their respective legal/privacy committee. Only the data that was required to address the research objectives was provided (the 'need to know' requirement) and could exclusively be used for the purpose as described in the data request form.

All the data sources that were made available for research by Statistics Netherlands were exclusively made accessible via their secure remote access environment. Access to this secure environment was requested before applying for the data sources and permission was granted to the researchers within the project team after passing a test on privacy regulations as put in place by Statistics Netherlands. All the data analyses took place within this secured remote access environment. To use the output of the analyses for public publications, permission was required from Statistics Netherlands for transferring the output outside the remote access environment. Statistics Netherlands has a strict policy regarding the risk of disclosure, and as such, they require an assessment to be conducted prior to allowing the use of their data. If there is deemed to be no risk of disclosure, the results can then be published. All output is checked by Statistics Netherlands before allowing it to be copied outside the secure environment.

Appendix S1 (see Supporting Information) displays detailed information on all the national data sources, sixteen in total, that were used to set up the Registry. Almost all these data sources were national covering, meaning that data on all Dutch citizens were included or on all Dutch citizens that made use of a specific type of care or support. The data stemming from the Dutch Nivel Primary Care Database was national representative, meaning that the data contained information on a selection of approximately 10 % of all Dutch citizens. This subset remained nationally representative in its socio-demographic and geographic composition.

Combining these data sources made it possible to identify persons with dementia as well as their cohabiting partner and provide information on a broad range of health, care and background related characteristics such as: their use of (out-of-office) GP care and hospital care (in terms of frequency and reasons for contact/admission), long-term residential care, home- and day care, their medication

prescriptions (not only dementia related), the presence of any other medical condition, their household income and their living area. Since the Registry is based on multiple reporting years, it also contains information on persons with dementia prior to their dementia diagnosis/start of their dementia medication use.

As described above, it was not possible to obtain access to data on dementia case management. This had two main reasons, related to: a) legal barriers to the use of the data; and b) barriers in registration practices of the home care organizations who organize the case management, as partner organizations of regional dementia care networks. With respect to legal barriers, home care organizations did not yet have a procedure in place which enabled the reuse of data in

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### BOX 1  Legal conditions for reusing data

The General Data Protection Regulation (GDPR) is applicable across all European Member States.[24] The objectives of the GDPR are twofold: to facilitate the free movement of personal data, and to protect the fundamental rights and freedoms of natural persons with regard to privacy and protection of personal data (Art. 1, GDPR). According to the GDPR, researchers need to obtain explicit consent from individuals to reuse the individual's personal health data.[25] Furthermore, under the GDPR legal framework, the principle of pseudonymization must be met in order to reuse personal data.[25]

Member States are allowed to adjust the application of certain aspects of the regulation to fit their national situation through specification clauses. Furthermore, the GDPR does not exclude pre-existing or newly adopted Member State law that sets out circumstances for specific processing of special categories of data in the public interest, for instance with regard to the processing of health data (Art. 9[4] GDPR).

In the Netherlands, the conditions for reuse of patient data for research have been described in a Code of Conduct, which states that, unless the research would be extremely sensitive, generic consent given at the level of the healthcare provider is a sufficient condition to release pseudonymized data for research, if (a) requesting explicit individual consent is not reasonably possible, for instance due to the death of the patient, or (b) the request for permission cannot reasonably be expected from the care provider. The exemption referred to under (b) would apply, for example, if there were such a large number of patients that reaching all those involved is too great an effort for the care provider, or that asking for permission would lead to a selective response from those involved, both potentially resulting in small study samples and consent bias, threatening the representativeness of the study sample.[25,26] In that case further conditions apply, such as that research must be in the general interest and that the patient did not opt out of the further use of their patient data for research.

accordance with the General Data Protection Regulation (GDPR) legal framework, see Box 1. With respect to barriers related to registration practices, there was substantial variation between home care organizations in the type and format of data that they record. Information was often stored in an unstructured way as 'free' text. In addition, the use of case management was not recorded systematically by most care organizations, which made it difficult to identify persons who received dementia case management.

## 3.3 | Stage 3: Data linkage

The main asset of the Registry is that it was based on linked national data for multiple reporting years from 16 different sources. The extent to which different datasets can be combined and communicate is called the Interoperability, and it is the third FAIR principle. One aspect of interoperability is the possibility to link data from different sources.

To link data, the same identifier should be used in each data source. In the case of the Registry it meant that the same identifier on an individual level should be available, since the Registry aimed to link data on the individual level of persons with dementia. Yet, to link data from various data sources on an individual level while guaranteeing that privacy rules were not violated, one-way pseudonymization was implemented.

The data sources brought together at Statistics Netherlands were pseudonymized either at the source or by Statistics Netherlands before becoming available for the Registry. Pseudonyms were based either on the national citizen service number, or a combination of postal code, date of birth and sex. Data were repseudonymized before being made available to the researchers.

The GP electronic health records data followed a different route regarding pseudonymization. This data was pseudonymized before being sent to Statistics Netherlands by a Trusted Third Party (TTP), an independent and reliable party that was in charge of running a controllable pseudonymization process.[27]

Other privacy sensitive information was provided on a higher level of aggregation whenever possible. For example, date of birth was converted to month and year, and only the numbers of the postal code (not the letters) were used to minimize risk of identification while still enabling use of age and residential area in the analyses.

Although the data sources were interoperable in the sense that it was practically feasible to link them after pseudonymization based on the pseudonymized citizen service numbers or a combination of postcode, data of birth and sex, we faced some interoperability challenges. For instance, not all reporting years from the various data sources were available at the same time, implying a time delay.

Furthermore, there were sometimes discrepancies in the data between time periods. This could for example be because of changes in recording guidelines, or changes in the reimbursement system such as suggested by Verheij et al.[28]

This was for instance the case with respect to anti-dementia medication use: from 2016 a decreasing trend was visible in the number of prescribed anti-dementia medication (ATC code N06D). Pharmacotherapy experts indicated that it could be related to the fact that the herbal remedy ginko biloba, which was used under the code N06D, was no longer compensated by insurers and at the same time there had been more reluctance in prescribing anti-dementia in recent years among general practitioners and at memory clinics. Consequently, less people with dementia could be identified on the basis of the medication data. This however did not change the fitness for purpose of the data, and study goals could still be served.[23]

## 3.4 | Stage 4: Reuse of the data and learning

The fourth stage of the development process relates to the Reusability of the data, the fourth FAIR principle. According to this principle, data are reusable if all three preceding FAIR principles (findable, accessible, interoperable) are met.

We found that it was indeed possible to link routine data sources and use this to provide insight into: (a) the background characteristics of a very large number of people with dementia in the Netherlands; (b) the various types of care and support that they might come across in their care trajectory, including GP care, hospital care and long-term care, as well as medication use. Furthermore, since we were able to link data including postal codes (on the level of municipalities) to individuals, it was possible to analyze the data on a regional level and to show regional variation in the use of care and support. The insights were presented in Dutch-language factsheets[23] one of which was translated into English.[29]

Although it turned out to be feasible to use routine data to provide insight into the use of care and support among persons with dementia, the data and the results from the study were far from self-explanatory. Ensuring correct interpretation by the public in general and by relevant health care professionals in particular was a challenge and needed substantial efforts. Guidance in this respect was important. This guidance was provided during a workshop for care professionals. During this workshop, professionals were informed that comparing regional and national figures could serve as a starting point for further discussions about the care provided for persons with dementia and which care improvements might be necessary. The figures based on data from the Registry showed for instance that specific types of care were used more often in some regions than in other regions and that there was regional variation in the waiting time between receiving an indication for a nursing home and moving to a nursing home. The professionals reflected on what could be the cause of this regional variation, and whether, for example, their organization and/or case managers could take anticipatory action. However, it took substantial effort from the researchers to stimulate the learning health system's actual learning part.

## 4 | DISCUSSION

Given the increased interest in the reuse and linkage of data for research and healthcare quality improvement,[6] this paper aimed to describe the lessons learned from the development of the Dutch

national Dementia Care and Support Registry and to draw lessons from this process. A unique feature of this Registry, is that it combines repositories of both health and census data, where other disease specific registries tend to be based on only one health or health care related data source. In line with the FAIR principles, only existing sources of routinely collected data were used for the development of the Registry.

The use of existing data sources avoided extra administrative burden, but it also ensued some limitations. For instance, the available data sources provide a relatively large amount of information about the use of care, but very little information about the quality of care. For the purpose of a learning health system, it is important that more information on the quality of care is recorded by healthcare professionals and subsequently transferred to regional or national databases. Combining data sources did, however, provide us with some information about practice variation, and it did enhance the intended discussions about the origin of this variation.

Another limitation was the lack of routine data on the types and stages of dementia, making it possible to study specific groups according to dementia type and stage. This is for instance possible in the Swedish dementia registry SveDem.[15]

Furthermore, we learned that data quality is an important issue. Organizations providing care to persons with dementia should learn how to record data in such a way that it is transferable and linkable with other data sources. This aspect can be a major challenge for the development of a registry based on reused routine data opposed to a registry that is developed based on the collection of new data (eg, Refs. [16,28]).

A lesson learned regarding the interoperability of existing data sources is that linkage is legally possible provided sufficient precautions are taken, including the pseudonymization of data. The interoperability of data is facilitated by the alignment of pseudonymization methods as well as by maintaining the same registration methods over the course of time. Changes in the way data is recorded can have consequences for the comparability of figures across years. If changes in registration methods do occur, clear reading instructions and explanations are required when publishing the figures, for example for healthcare professionals who make use of the data for quality improvements.

Interoperability also refers to the systems and platforms utilized to facilitate data sharing. With respect to this issue, we found that the national data sources could be seamlessly integrated within the secure environment of Statistics Netherlands as the data was stored in formats that were compatible with their systems. However, data from care organizations could not be integrated as the recorded formats were not compatible.

Information derived from routine health data might not be easy for healthcare professionals to work with and it is therefore highly recommended to involve the end users of a registry at an early stage in deciding what would be relevant output and the best way of providing feedback reports of the data. Furthermore, guidance is highly advisable on how the information from a registry can be used in discussion or reflection meetings, within organizations and their networks.

The data of the Registry is stored as STATA files within the protected environment of Statistics Netherlands. Access to the data can be granted only to authorized researchers who have obtained access to the Statistics Netherlands environment through the application procedure, and with the permission of the original data sources. Although this access is not free of procedures or costs, descriptive data has been made available through public factsheets (eg, Ref. [29]) and an online dashboard currently under development. However, as access to the data is subject to certain conditions, the Registry is currently not fully compliant with the FAIR principles.

To conclude, although it is an extremely time-consuming effort, it is possible to set up a national registry based on multiple existing health and census data sources that provides rich data for research and quality improvement. To use a registry for quality improvement in practice, it is of key importance to involve policy makers and healthcare professionals in the development of such a registry and provide guidance on how to learn from the data and to improve the quality of care.

## CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflicts of interest pertaining to the research presented in this paper.

## ETHICS STATEMENT

This study has been approved by the ethics committee of the VU University Medical Center and is in accordance with the governance code of the Nivel Primary Care Database, filed under number NZR-003.19.018. As pseudonymized data were used that were collected for routine administrative registration purposes, the informed consent of the participants was not necessary. Patients were informed by their GP about the use of their pseudonymized health data and were given the opportunity to object.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.