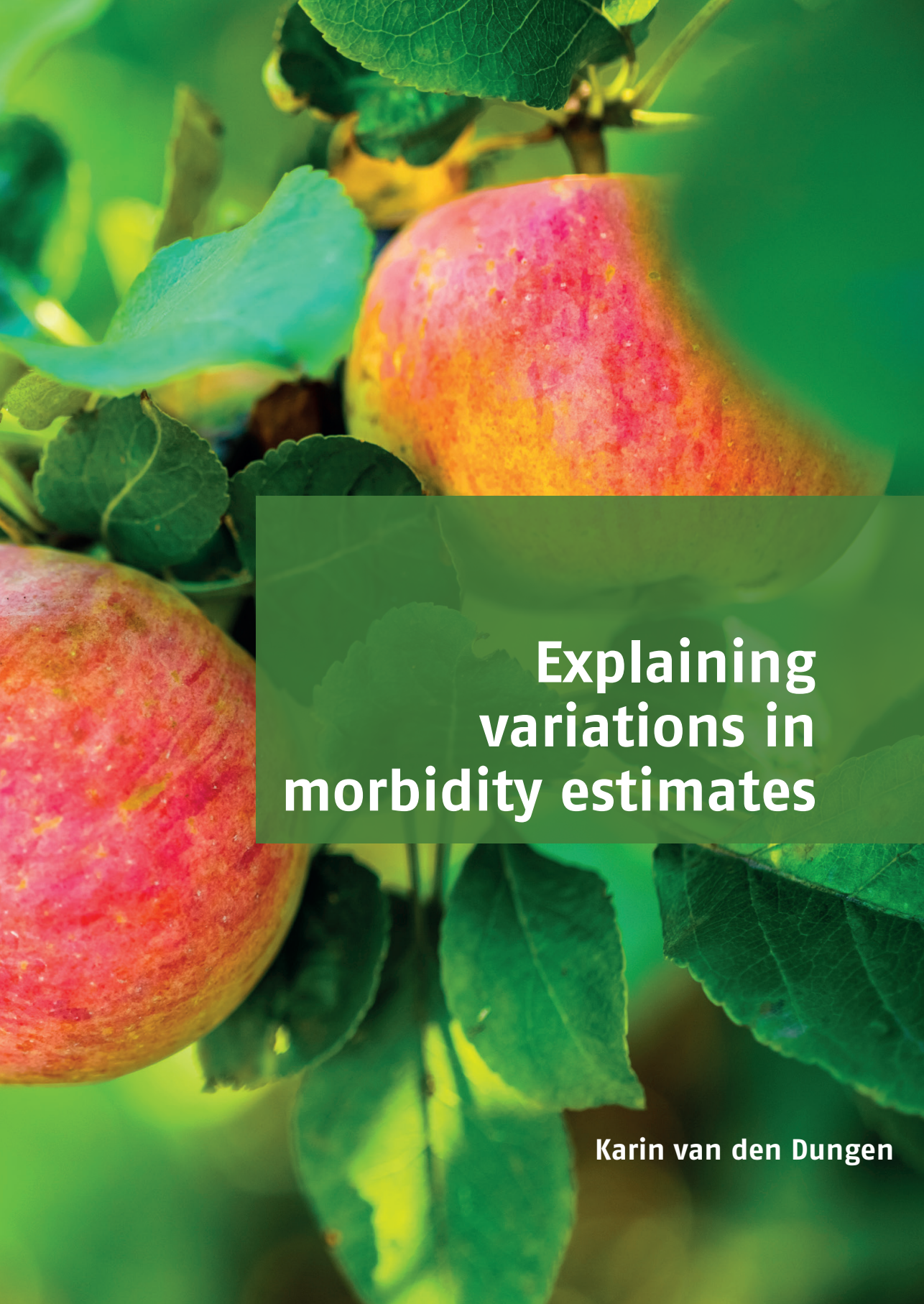

Explaining variations in morbidity estimates

Karin van den Dungen

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Data from general practice registration networks

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Proefschrift

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Table of Contents

CHAPTER 1

General introduction

POPULATION HEALTH AND MORBIDITY ESTIMATES

Health policy makers need objective information about the health status of the population. Estimates of disease incidence and prevalence, life expectancy, and mortality are core indicators of population health and health care needs. Information about which diseases occur most frequently and which health problems deserve priority provides guidance to public health policy. Incidence and prevalence rates are also important inputs for burden of disease studies and of simulation models designed to making projections of future population health.[1, 2]

The frequency of diseases is usually expressed in incidence and prevalence rates. Incidence is expressed as the number of newly diagnosed diseases or the number of persons falling ill within a certain time period. Prevalence is the number of patients with a specific health problem at a certain point in time (point prevalence), regardless of the date of onset of the disease. Prevalence can also be expressed as all patients with a specific health problem during a defined period of time (period prevalence), which is often more informative in health problems which are acute or recurring.[3]

DATA-SOURCES FOR MORBIDITY ESTIMATIONS IN THE NETHERLANDS

The Public Health Status and Foresight reports of the National Institute of Public Health and the Environment (RIVM) that are published every four years integrate epidemiological information of a diversity of data sources to describe the population's morbidity in the Netherlands. The information on the incidence and prevalence of diseases comes from a variety of data sources, as for example health care registries, health examination surveys, and health interview surveys.[4-6]

Health examination surveys include a systematic examination of individuals (usually a random sample of the total population) for the absence or presence of morbidity. These surveys give an objective and accurate indication about the population's health. Unfortunately, these surveys require extensive effort (time-consuming), are expensive, and are also susceptible for bias due to non-response. Health interview surveys are a faster and cheaper alternative. Although these surveys give a general picture of the diseases in a population, the observed morbidity is based on self-reported health problems. Two possible drawbacks can be identified, the first is the overestimation of mild morbidities, which is less relevant regarding to the burden of disease and health care utilisation. A second problem is the underestimation of prevalence figures as patients do not always recognize their conditions.[7, 8] Furthermore, it is difficult to discriminate between incidence and prevalence cases.

Other sources for morbidity estimations are health care registries, such as disease registries, hospital registries, and general practice based registries. These sources have the advantage that they include objective information about diseases diagnosed by a health care professional, and have a longitudinal design, which makes analysis of time-trends possible. A general drawback is that these registries only include health problems that have been presented to health care.

Disease registries e.g. a cancer registry enclose objective and valid information about one specific disease or disease-category, but are only available for a limited number of diagnoses and have no information about multimorbidity. Hospital registries hold information about health care utilisation in secondary care, and therefore only include more severe cases of diseases which require hospitalisation. General practice based registries include a broad spectrum of health problems as nearly all health problems are first presented in general practice and over 90% of these health problems is managed solely in primary care.[8-10]

DUTCH GENERAL PRACTICE

The situation of the Dutch general practice will be largely described as it appeared in 2007, because the data used in this thesis were collected in that specific year. The general practitioner (GP) is the core health care provider in the Dutch healthcare system and acts as gatekeeper for specialist care. This means that referral by a GP is necessary for patients to obtain secondary care. Another important characteristic of the Dutch healthcare system is that almost all people are listed (registered) with a GP and therefore the epidemiological denominator (number of persons at risk) can easily be measured. All Dutch citizens are required to be insured for basic health care, which is identical for all people. In 2007, a no-claim premium reimbursement was set, though, this did not include GP care.[11] This facilitates the accessibility of health care, as people have initially no financial barriers to contact their GP. As a result, general practice based morbidity data contains the information of patients suffering from diseases in various stages of their disease and of all patient groups without selection regarding age, gender, socio-economic status or ethnicity.[11, 12]

In 2007, on average 2,331 patients were registered with one full-time equivalent GP. About 22 percent of the Dutch GPs was working in a solo practice and nearly fifty per cent in a group practice. The number of multi-disciplinary health care centres is growing.[11, 13]

General practitioners' first priority is to provide high quality patient care. GPs record information in electronic health records (EHR) to account for the given patient care. Structuring of this information gives an overview of the patients' health problems. For daily patient care, up-to-date, complete and valid information is necessary. In the Netherlands, many general practices participate in a general practice registration network (GPRN). GPRNs collect information from individual practices and collate the data in a (central) database for other purposes than daily patient care. This routinely recorded data is widely used in research, e.g. to evaluate health care, to estimate morbidity rates or to observe health inequalities.[14]

SHORT HISTORY OF DUTCH GENERAL PRACTICE REGISTRATION NETWORKS

In the Netherlands, more than ten GPRNs collect routinely recorded data from general practice. After the 1950s, the profession of general practitioner became an important research topic and

the need for information about morbidity (contacts and diagnoses) and health care (interventions, referrals and prescriptions) in general practice grew. Oliemans described in his doctoral dissertation (1969) the first continuous morbidity registration in general practice.[15] In 1966, five GPs continuously recorded data about doctor-patient contacts, including morbidity using the so-called E-list (named after Eimerl, one of the composers), a coding system for diagnoses presented by their patients.[15, 16] As a follow up of Oliemans' work, Professor Frans Huygen and colleague Van Thiel started the Continuous Morbidity Registration (CMR) in the village of Lent, near Nijmegen.[17] They recorded all disease episodes presented in their practice, including diagnoses made by specialists after referral. CMR was expanded to four practices (1971) and these practices have been recording ever since.[17]

Since the introduction of the electronic health record (EHR), collecting data became easier. Today, virtually all GPs use an EHR for patient care. In recent years, EHRs have been developed and structured recording in 'episodes of care' is increasing. Episodes of care include all available information about the management of a specific health problem.[3] An episode of care starts with the first presentation of a health problem to general practice and ends with the last encounter for the same problem. Episodes of care can be used as a proxy for the 'episode of disease', which starts at the onset of the problem and ends if a patient is cured or dies. This structuring of routinely collected data is important to have an overview of health problems in general practice and the care given for a specific disease.[18, 19]

RECORDING AND CLASSIFICATION

Information on morbidity generated from general practices is an important data source incidence and prevalence of common diseases. When considering morbidity estimated from data of GPRNs, it is important to realize that it exclusively includes information of health problems presented to health care. For that reason, the estimated morbidity is, by definition, lower than the actual morbidity of a given disease measured in the general population. Besides this, also the framework of a GPRN has an influence on the measured morbidity. Roughly, two types of GPRNs have been developed, GPRNs based on patient-GP contact data and GPRNs based on health problems data (in new EHRs known as 'episode with attention status' or activation code). The latter exclusively collect information of disorders present on the so called problem-list, which includes only health issues that are permanent, chronic (duration ≥ 3 months) or recurring and need special attention of the GP. The contact based GPRNs collect information about all health problems recorded in each contact. In this thesis a broad definition of contacts is used, including face-to-face contacts, telephone consultations, letters from medical specialists, prescriptions etc.[8, 19]

The classification systems to record morbidity in the EHR have been developed. In 1987, the WONCA published the International Classification of Primary Care (ICPC), a disease classification to code the reason for encounter, the diagnostic process of interventions, preventive services, administrative procedures, and diagnoses.[20] This classification is specially designed to fit the working process of GPs. ICPC has been tested and found to be practical and reliable in general practice, with less than 3

per cent recording errors. In 2007, most Dutch GPRNs used the ICPC-1 to code morbidity, one GPRN used the modified Nijmegen E-list and two GPRNs used the revised version of ICPC, the ICPC-2.[3, 16, 20, 21]

RATIONALE AND AIM OF THE THESIS

Morbidity estimations derived from the Dutch GPRNs show considerable differences in incidence and prevalence figures between the networks. Gijsen and Poos (2006)[8] illustrated these differences with the incidence rates of myocardial infarction and the prevalence of rheumatoid arthritis, see figure 1. They could not explain these differences, but they suggested that differences in registration rules, definitions, practice population and quality aspects might play a role in explaining the observed differences among GPRNs.[8]

The aim of this thesis is to contribute to a better understanding of the differences in incidence and prevalence figures between Dutch GPRNs, and ultimately, to obtain a qualitative better estimation of population health. To do so, two steps are taken:

1. Identification of factors that potentially influence the differences in morbidity estimations between GPRNs.
2. Analyzing the effects of these factors on the variation in morbidity estimation between Dutch GPRNs.

OUTLINE OF THE THESIS

The focus of this thesis lies on the differences in morbidity estimates in terms of incidence and prevalence rates between Dutch GPRNs. In **chapter 2**, we identify the different categories of factors that may be responsible for the variation in morbidity estimations between GPRNs. With respect to these factors, the different GPRNs in the Netherlands are characterized. **Chapter 3** describes the influence of population characteristics of the practice population included in the GPRNs on the differences in morbidity estimations between these networks and in **chapter 4** the influence of various practice characteristics on this variation is considered. In **chapter 5,** we investigate which aspects are important regarding the quality of general practice based data from the perspective of the networks themselves. In **chapter 6**, we describe the quality rules practiced by eight GPRNs and explore how these rules fit the quality domain established in chapter 5. Finally, **chapter 7** reflects on factors considered in the previous chapters and discusses the implications for using general practice based data to describe population health and GPRNs. This chapter ends with an agenda for future research.

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CHAPTER 2

What factors explain the differences in morbidity estimations between General Practice Registration Networks in the Netherlands? A first analysis

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ABSTRACT

Background: Information on the incidence and prevalence of diseases is a core indicator for public health. There are several ways to estimate morbidity in a population (e.g. surveys, health care registers). In this paper we focus on one particular source: general practice based registers. Dutch general practice is a potentially valid source because nearly all non-institutionalized inhabitants are registered with a general practitioner (GP) and the GP fulfils the role as "gatekeeper". However, there are some unexplained differences between morbidity estimations calculated from the data of various general practice registration networks (GPRNs).

Objective: To describe and categorize factors that may explain the differences in morbidity rates from different GPRNs and to provide an overview of these factors in Dutch GPRNs.

Results: Four categories of factors are distinguished: "healthcare system", "methodological characteristics", "general practitioner", and "patient". The overview of eleven Dutch GPRNs reveals considerable differences in factors.

Conclusion: Differences in morbidity estimation depend on factors in the four categories. Most attention is dedicated to the factors in the "methodological characteristics"' category, mainly because these factors can be directly influenced by the GPRN.

Keywords: General practice; Medical registration/data collection; Incidence and prevalence; Public Health; Morbidity measures

INTRODUCTION

Morbidity rates are core indicators of public health and health care needs of a population; therefore, valid information on incidence and prevalence rates of diseases is important.[1] There are several ways to estimate morbidity rates in a population, such as health interview surveys, health examination surveys, and health care registers, of which general practice based registers are an example.[1] Compared to morbidity rates estimated from health interviews, an important advantage of morbidity rates estimated from care- based data is that health problems are diagnosed by a physician.

In the Netherlands, and some other countries like the UK, nearly all non-institutionalized inhabitants are registered with a general practitioner (GP).[2-4] Additionally, Dutch GPs fulfil the role as "gatekeeper": when patients seek medical care from a medical specialist, they have to be referred by their GP, and after consultation, the medical specialist reports back to the patient's GP.[5] GPs have contact with patients suffering from diseases in various stages of their disease and with all patient groups without selection regarding age, gender, socio-economic status or ethnicity.[6-9] This makes Dutch general practice a potentially valid source of information on morbidity.

Many GPs keep an electronic medical record (EMR), primarily for direct patient care.[10] When several GPs collaborate in the collection of patient information (e.g. using a uniform data collection method, and the same registration rules and classification system), and gather their information from separate EMRs into a central database, a general practice registration network (GPRN) is established.[9,11,12] Besides estimating morbidity figures, GPRNs can be used for a variety of purposes: they can act as an index for selecting patients with certain characteristics for research, for research into the course of illnesses, health care utilization, quality of care, and for education or management.[5]

In the Netherlands, there are multiple continuously recording GPRNs. The Continuously Morbidity Registration Nijmegen (CMR), the oldest Dutch GPRN, dates back from 1967.[9] Since then, many other continuously recording GPRNs have been established, and several continuously operating GPRNs still exist today.

Gijsen and Poos[13] demonstrated how data from GPRNs can be used to estimate morbidity in the Dutch population. They also showed that these estimations differ between various Dutch GPRNs. An example of these differences, the prevalence rates of rheumatoid arthritis calculated from data of five different GPRNs, is presented in box 1.[14]

To increase the utility of GPRN data for morbidity estimations in the Netherlands, a research project has been set up. The first part of this project is to gain more insight into differences in morbidity estimations between GPRNs. In this article we describe and categorize several factors that may explain the differences in morbidity rates as calculated from data provided by the Dutch GPRNs. In addition, we give an overview of several Dutch GPRNs and consider their dissimilarities as a first step towards explaining these differences.

Box 1 Prevalence rates of rheumatoid arthritis from five General Practice Registration Networks (GPRNs) in the Netherlands

The National Institute for Public Health and the Environment uses information about diseases derived from GPRNs for the estimation of morbidity rates presented in the National Public Health Compass.[14]

Prevalence rates‡ of rheumatoid arthritis (per 1000 patients)

	CMR-Nijmegen	LINH	RNH	RNUH LEO	Transition Project
Men	5.11	2.97	9.4	6.83	3.06
Women	6.40	5.92	13.49	13.19	7.18

‡ These rates are based on data from GPRNs, which were available in 2005

FACTORS INFLUENCING MORBIDITY ESTIMATES FROM GPRNS

The factors described in this section potentially influence morbidity estimates calculated from GPRNs. The categories of factors are based on different levels, such as country, region, practice and doctor, as described by Marinus[15]. These levels relate to different sources of variation, which we translated into the GPRN situation to which we added the 'patient'-level as an additional source of variation.[15] Explanations for these factors are based on findings from previously published studies. It is important to realize that the occurrence of diseases in the population determine morbidity, but that the different factors described here influence the estimation of that morbidity. The categories and factors are presented in figure 1.

Within a GPRN, we distinguish four categories of factors, "healthcare system", "methodological characteristics of the network", "general practitioner" and "patient". The factors and sub-factors are shown as independent, but they are often interrelated.

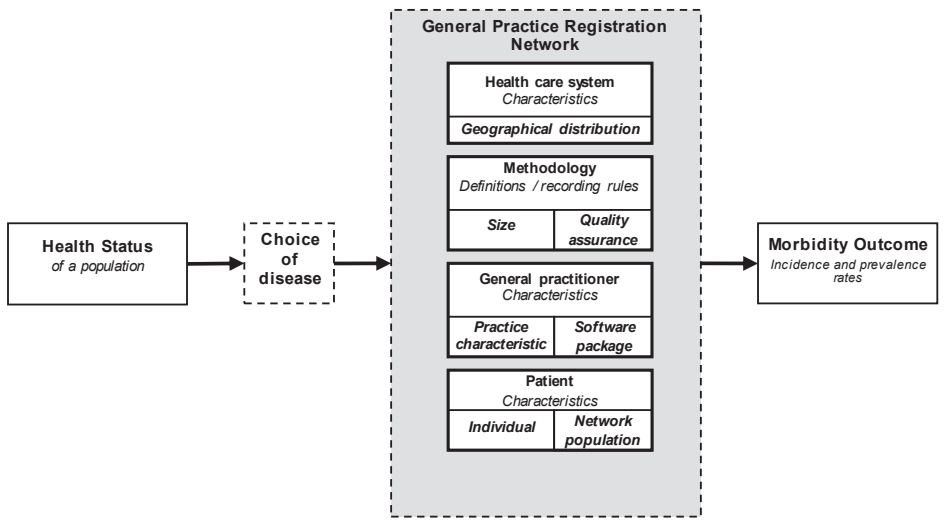

Figure 1 Factors influencing morbidity figures of General Practice based Registration Networks

The healthcare system refers to the levels of country and regions. The healthcare system defines the accessibility of GPs and other healthcare professionals in a specific country and the rules or laws to which GPs have to comply.[3,16] If medical specialists or other healthcare providers are directly accessible and do not report information to the patient's GP, the completeness of the information from general practice based data about morbidity will be reduced.[5] Most healthcare system related characteristics are identical for an entire country, but within a country regional differences also exist. Examples of regional differences are the distance between the general practice and the nearest hospital, the organization of GP out-of-hours services and the cooperation with other healthcare facilities.[17] The geographical spread of the GPRN is also an important factor.[18]

The second category of factors includes the methodological characteristics of the GPRN. The operating definitions and registration rules affect the validity and reliability of the data for estimating morbidity rates.[13,19,20] A large range of factors concerning definitions and rules are important: Which morbidity data are included in the GPRN database (only chronic conditions or also acute, minor health problems)? Which classification system or diagnostic criteria, if any, are used to record the morbidity information? What are the operational definitions of incidence and prevalence to determine morbidity? How are all patients with a specific disease counted in the GPRN (numerator)? Are data from all contacts with the patient taken into account or only from face-to-face contacts? Is all information received by a GP on morbidity taken into account, such as information from medical specialists?[21,22] Another, important methodological aspect is size, i.e. the sampling size of the total population of interest (in our case, the total Dutch population). The sampling size influences the power of the estimations.[23]

The methodological characteristics of a GPRN are strongly influenced by the main purpose of the GPRN. As Knottnerus[24] comments: "a diversity of objectives inevitably brings diversity of methods and systems." The definitions and registration rules of a GPRN are derived from its purpose.[19] In addition, "quality assurance" is an essential methodological factor; it determines, for example, GPs' compliance with the rules and therefore also influences the validity and reliability of the data.[9] Key issues here are the application of minimum quality criteria, systematic checking of the data, and feedback to the GPs about data quality, all of which are incentives for providing high-quality data.[23,25]

The third category of factors regards the "general practitioner" and refers to the influence of GP characteristics within a GPRN on the morbidity figures. Marinus[26] studied this factor and concluded that morbidity rates vary considerably between GPs.[26] Research also showed that this variation depends on the disease under study.[27] Less variation in morbidity rates between GPs is found regarding diseases that are easy to recognize or have clear diagnostic criteria, such as herpes zoster or diabetes mellitus.[8,15,28-30]

The factor "general practitioner" also contains practice characteristics. These characteristics include, for example, the number of GPs working in a practice, whether GPs work in a health care centre or in separate practices, the intensity of cooperation between GPs, and the employment of other personnel, such as practice assistants and practice nurses.[29] Less variation in contact frequency is found between GPs within a practice compared to differences between practices.[29]

The software package used to record patient information, the actual EMR, is also a factor that can explain differences between GPRNs. For example, previous research showed some unexpected differences in consultation rates related to these information systems, even after adjustment for explaining factors.[29]

Box 2 Eleven Dutch General Practice Registration Networks

Abbreviation	Full name (Dutch)	Full name (English)
ANH-VUmc	Academisch Netwerk Huisartsgeneeskunde, Vrije Universitair medisch centrum	Academic General Practice Network of VU University medical centre
CMR-N	Continue Morbiditeit Registratie Nijmegen	Continuous Morbidity Registration Nijmegen
HAG-net-AMC	Huisartsen Netwerk Academisch Medisch Centrum	General Practice Network Academic Medical Centre
IPCI	-	Integrated Primary Care Information
LINH	Landelijk Informatie Netwerk Huisartsenzorg	Netherlands Information Network of General Practice
RNG	Registratie netwerk Groningen	Registration Network Groningen
RNH	Registratie net huisartspraktijken	Registration Network Family Practices
RNUH- LEO	Registratie Netwerk Universitaire Huisartspraktijken Leiden en omgeving	Registration Network of General Practitioners associated with Leiden University
SMILE	Studie naar Medische Informatie en Leefwijzen in Eindhoven	Study into Medical Information and Lifestyle in Eindhoven
Trans	Transitie Project	Transition Project
HNU	Huisartsen Netwerk Utrecht	The Utrecht Network of General Practitioners

The category of factors related to the "patient" is divided in individual patient characteristics ("case mix") and the GPRN population as a whole. Patients differ from each other in many aspects, such as age, gender, socio-economic status, ethnic origin, and lifestyle.[31] These aspects determine the probability of getting a disease and whether a person seeks help and contacts his or her GP.[32] Furthermore, the representativeness of the population of all practices participating in the GPRN, compared to the population of interest is important for the generalizability of the results.[19]

GPRNS IN THE NETHERLANDS

A first step towards understanding the differences in morbidity estimations between various GPRNs is to review these GPNRs with respect to the factors from the four categories. The GPRNs described in this article meet two criteria: they continuously collect data concerning all morbidity presented in general practice and they are part of a long-term project. Eleven Dutch GPRNs fulfilled these criteria; the abbreviation and full name of each GPRN is presented in Box 2.

The authors from RIVM created a list of GPRN characteristics, which includes different aspects of the main categories of factors. Using available background information in books, reports, and articles, they filled this list for each GPRN. The network coordinators of each GPRN checked and completed the list. Table 1 shows the characteristics of the eleven GPRNs.

All used GPRNs function within the Dutch health care system, so little difference is expected in terms of the healthcare system. The only differences may occur with respect to geographical differences, as only LINH and IPCI operate nationally.

Methodological characteristics, however, do vary between GPRNs. The sizes of the GPRNs range from 13,000 to 600,000 registered patients with a number of GPs and practices between 8 and 362 and 3 and 80 respectively.

The main goals of the GPRNs can be divided into two objectives, where providing input for and conducting scientific research are common aims. One objective is to generate information about general practice in general; the other objective regards the provision of a sampling frame.

The method used to establish the epidemiological numerator depends on several characteristics, such as the type of network, the recording rules of the GPRN, the used classification system, and software package used. In the Netherlands, there are two main network types, "contact" and "problem list" based GPRNs. "Problem list" based GPRNs only contain information about the health problems of a patient that are permanent, chronic (duration longer than six months), or recurrent.[18] HAG-net-AMC and RNH are 'problem list' based GPRNs and consequently count the diseases recorded on the 'problem list' to establish the numerator. "Contact" based GPRNs store the information about all patients' health complaints and diagnoses from all contacts with the practice in their database. Information from several contacts is structured into "episodes" for a specific disease. Such 'episodes' are assigned by the GP. To establish a numerator all episodes are counted. CMR-N, HNU, RNG and Trans count all "episodes" for a specific disease. ANH-VUmc, RNUH-LEO and SMILE extract information from both methods (problem list and episode construction by GPs) into their database. LINH is a "contact" based GPRN, which constructs the episodes afterwards using EPICON, a computerized algorithm which links separate contacts into one "episode".[33]

The most commonly used classification system for classifying diseases is ICPC-1. Other classifications in use are the ICPC-2 and E-list. All GPs in the included GPRNs record in an electronic medical record software system, but vary with regard to the software package. A GPRN usually utilizes only one or two software packages. A software package sometimes forces the GP or the GPRN to record according to a certain method.

GPRNs use different operational definitions of episodes. CMR-N includes all information a GP has about a patient in determining morbidity. SMILE, RNG and LINH include data about all GP-patient contacts, including indications for prescriptions. For "contact" based GPRN databases, the completeness of the numerator depends on what information is recorded. "Contact" based GPRNs

Table 1 Outline of eleven Dutch General Practice Registration Networks (GPRNs)

	ANH-VUmc	CMR-N	HAG-net-AMC	HNU	IPCI	LINH	RNG	RNH	RNUH- LEO	SMILE	Trans
Healthcare system											
Localisation	Amsterdam, Amstelveen and Haarlem	Nijmegen and surrounding area	Care area AMC Amsterdam	Province Utrecht	Throughout the Netherlands	Dutch representation	Groningen, Hoogezand-Sappemeer and Hoogeveen	Province of Limburg	Leiden and surrounding area	Eindhoven	Amstelveen and Franeker
Methodological aspects											
- *Sample size*											
Size	70.000	13.500	57.000	56.210	600.000	350.000	30.000	87.780	30.000	56.000	13.160
GP/ practice	47 / 12	11 / 4	44 / 37	35 / 22	362 / not counted	160 / 80	17 / 3	65 / 22	20 / 4	32 / 9	8 / 5
- *General information*											
Goal	Improving quality of family medicine	Generation of epidemiologic data for diseases	Providing a sample framework for scientific research	Collecting longitudinal data for scientific research	Collecting data from primary care for post-marketing surveillance	Providing information about GP care, quality of care and public health	Systematic collection of information for patient care	Providing a sample framework for scientific research	Supporting scientific research, education and GP care in general	Collecting hybrid data collection for research and sampling framework from questionnaires and GP care	Formulating, characterizing and describing GP based epidemiology
Type of network	Problem list and contact based GPRN	Contact based GPRN	Problem list based GPRN	Contact based GPRN	Contact based GPRN	Contact based GPRN	Problem list and contact based GPRN	Problem list based GPRN	Problem list based GPRN	Problem list and contact based GPRN	Contact based GPRN
Classification#	ICPC	E-codes	ICPC	ICPC-2	ICPC	ICPC	ICPC	ICPC-1	ICPC-1	ICPC-1	ICPC-2/ ICD10
- *Definitions*											
Numerator	Episodes[a] and problems[b]	Episodes[c]	Problems[b]	Episodes[a]	Complete records[d]	Contacts[e]	Episodes[f]	Problems[b]	Episodes[a] and problems[b]	Episodes[a] and problems[b]	Episodes[g]
Data available											
Recorded information	Morbidity, prescription and referrals	Morbidity, referrals and hospital admission	Morbidity, prescriptions and intervention	Morbidity, prescriptions referrals and intervention	Morbidity, complete records	Morbidity, prescriptions referrals and intervention	Morbidity, prescriptions referrals, type of contact	Morbidity, prescriptions medication dossier	Morbidity, prescription, medical history, diagnostic dossier and referrals	Morbidity, prescriptions, referrals, number and type of contacts	Morbidity, all proceedings in practice§
Recording; out-of-office hours, phone contacts, visits	No agreements	Out-of-hours and telephone contacts and visits	Differs per location	telephonic contacts and visits but incomplete	No agreements	Telephonic and email contact, and visits	Out-of-hours and telephone contacts and visits	No	Out-of-hours (except one practice) and telephone contacts and visits	Telephone contacts and visits	Yes all out-of-office hours, only employee GP
Recorded contact with other employees?*	Variable between practice and GPIS	Yes Assistant	Yes Assistant	Yes Assistant	Yes But no agreement	Yes Assistant and nurse practitioner	Yes Assistant, nurse practitioner and locum tenens	Contacts are not used in database	Yes Assistant, physician assistant and locum tenens	Yes	Yes Assistant, physician assistant and locum tenens
Quality assurance											
Control of data after extraction	Yes Impossible or illogical combinations	Yes File-size and mis-classification	Yes Impossible or illogical combinations and missing values	Yes ID codes and completeness	Yes Completeness and internal consistency	Yes Completeness and internal consistency	No	Yes Impossible or illogical combinations or values	Yes Population, impossible values, doubles, missing links, completeness	No (in future)	Yes Doubles
Classification agreements	Instruction GP	Training GP	Internal training GP	Expertise promotion	Absence of paper registration	Explicit documenta-tion, introduction period of a new GP	Explicit documenta-tion	Training GP, coding assistance (RNH web, RNHassistant program, help file)	Internal training GP and explicit documenta-tion	Instruction GP	In- and exclusion criteria registered in ICPC-2
Feedback about data to the GP	?	Yes	Yes	Yes GP info-net	Yes	Yes	Yes annual report & newsletter	Yes	Yes	Yes	Yes
Meetings	Yes Monthly and 2 per year	Yes Monthly	Yes 2 per year	Yes 5 per year	Occasionally	Optional Once a year	Yes 2 per year and a weekend	Yes 2 per year	Optional Once a year	Optional	Yes, 6-weekly, 1 weekend
Contents of the meetings	Education GP workshops	Classification difficulties, consensus	Quality of the registration, special items	Education and registration	Scientific topics	Not applicable	Registration problems	Consensus	Not applicable	Registration difficulties, benchmark	Classification problems Special items
Information system											
Software package	OmniHIS, MicroHIS and Medicom	Promedico	Mira & MicroHIS 8	MicroHIS and Promedico	Elias, Promedico, MicroHIS, Medicom and HetHIS	Arcos, Mira, Promedico, OmniHIS, MicroHis, Elias and Medicom	MicroHis	MicroHis and Zorgdossier	Medicom	Medicom	TransHIS
Patient characteristics											
Patient characteristics	Year of birth, gender, zip code, patient category (fixed or not fixed)	Gender, age, social class, education level, family situation, occupation, zip code	Date of birth, gender, family situation (ethnicity)	Date of birth, gender, family situation, zip code	Gender, age, family situation, patient category (fixed or passer-by)	Date of birth, gender, zip code, family situation, GP code, patient category (fixed or passer-by)	Date of birth, gender, zip code, GP code	Date of birth, gender, zip code, family situation, education (>25 years old), status fixed or not	Age, gender, number of family members	Date of birth, gender, educational level, marital status, living arrangementand zip code	Date of birth, gender, family situation, zip code

Classification system according to the GPRN, *Employees, other than the practice GPs recording into the EMD, a Counting year prevalence, thus after at least one GP-patient contact in the reference year, b Use all diseases or complaints which are permanent, chronic or recurrent or need to be at the GP's attention, c Use all information about morbidity a GP receives, d Depends on the research question, whole record information is possible (free text, diagnoses, prescriptions, specialist letters etc.), e Episode construction after collection in database, f Start with morbidity episodes, with possible completion with prescriptions, referrals and interventions, g Use all information about what takes place in general practice, § all proceedings in practice, including type of contact, reason for contact, episode of care status, coding-changes, referrals, test-results, interventions, prescriptions etc.

vary substantially in this respect. Data from face-to-face contacts with the GP and home visits during weekdays are usually recorded, as well as telephone contacts. Data regarding contact during out-of-hours services are recorded the least. Data about contacts with practice nurses and assistants are recorded when this is important for patient care, but these entries are often incomplete.

Nine GPRNs check for misclassification and impossible or illogical data combinations after extraction from the practices. HAG-net-AMC, HNU, IPCI, LINH and RNUH-LEO also monitor data completeness.

To ensure a reliable and valid registration of diseases, different methods are being used: training of GPs, explicit documentation, and meetings between GPs about registration difficulties and consensus procedures. Ten out of the eleven registrations give feedback to the GPs about their recording performance.

The epidemiological denominator indicates the total population at risk of all practices participation in the GPRN. It is possible that the composition of the population with respect to socio-economic status, ethnicity, level of urbanization, etc. differs between the GPRNs. Moreover, several GPRNs are located in limited regions of the country, and it is well-known that the health status of the population differs between regions.[34] For all GPRNs, the population's age and gender distribution is known. Eight out of ten GPRNs also record family characteristics, such as household size. CMR-N, RNH and SMILE also include socio-economic status indicators, such as education and occupation. Most GPRNs include the numerical part of the zip codes of the addresses of their population from which socio-economic status can be roughly estimated.[35]

DISCUSSION

In this article, several factors that may explain the differences in morbidity estimates from various GPRNs are described. Four main categories of factors are distinguished. In future research, we will investigate the influence of these different factors on morbidity estimations. In addition, an overview is given of eleven Dutch GPRNs, which reveals considerable differences between GPRNs. In this article, most attention is dedicated to the factors in the "methodological characteristics" category. One reason for this is that these factors can be directly influenced by the GPRNs, unlike for example the healthcare system or patient factors.

Using the differences in estimations of the prevalence of rheumatoid arthritis (RA) between five GPRNs (box 1) and the variation of factors among these GPRNs we can identify several possible explanations. RNH and RNUH-LEO show relatively high estimations, which may be explained by the fact that both GPRNs are problem-based networks. A diagnosis on the "problem list" remains in the database until the patient is cured or the disease is no longer important for the patient's care, whereas contact-based databases LINH and Trans, only count prevalent cases of RA when contact related to RA has taken place in a particular year. Another difference is that CMR-N uses the E-list for classification of RA, in contrast with the other networks which use ICPC. In the ICPC classification, the code for RA also contains other rheumatoid disorders such as ankylosing spondylitis, whereas

the E-list code only includes RA. However, this was not reflected by a lower estimation of RA in the CMR-N. At this point, the only conclusion can be that explaining the differences is complex.

The other categories of factors that might explain the differences may not be influenced by the GPRN, but they cannot be ignored. The geographical area covered by the Dutch GPRNs vary. Because some GPRNs act regionally instead of nationally, a part of the variation in the morbidity rates is probably based on real differences, as the health status of the population is not equally distributed over the country.[34]

The composition of the practice, GP and patient characteristics in relation with the entire population of interest, determine the representativeness of the GPRN population. In addition to adjusting for gender and age of the GPRN population one could also adjust for socio-economic status. Direct measurements of socio-economic status, such as education, are preferred to indirect measures such as a zip code.

In further research we want to study the influence of the factors described in this article. It would be particularly interesting to establish which factors affect the validity of the estimations of morbidity figures. However, we do not expect that the factors presented here will explain all variance in morbidity figures, because the process of diagnosing is known to be a complex interaction between knowledge, the wishes of the patient, the GP's opinion, and other factors.[29]

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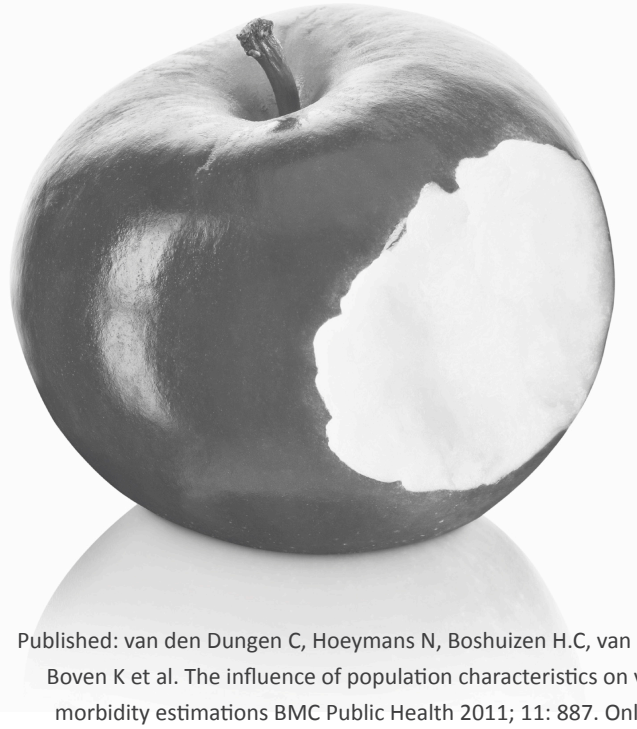
CHAPTER 3

The influence of population characteristics on variation in general practice based morbidity estimations



C van den Dungen
N Hoeymans
HC Boshuizen
M van den Akker
MCJ Biermans
K van Boven
HJ Brouwer
RA Verheij
MWM de Waal
FG Schellevis
GP Westert

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ABSTRACT

Background: General practice based registration networks (GPRNs) provide information on morbidity rates in the population. Morbidity rate estimates from different GPRNs, however, reveal considerable, unexplained differences. We studied the range and variation in morbidity estimates, as well as the extent to which the differences in morbidity rates between general practices and networks change if socio-demographic characteristics of the listed patient populations are taken into account.

Methods: The variation in incidence and prevalence rates of thirteen diseases between six Dutch GPRNs and the influence of age, gender, socio economic status (SES), urbanization level, and ethnicity are analyzed using multilevel logistic regression analysis. Results are expressed in median odds ratios (MOR).

Results: We observed large differences in morbidity rate estimates both on the level of general practices as on the level of networks. The differences in SES, urbanization level and ethnicity distribution between the networks' practice populations are substantial. The variation in morbidity rate estimates between networks did not decrease after adjusting for these socio-demographic characteristics.

Conclusion: Socio-demographic characteristics of populations do not explain the differences in morbidity estimations between GPRNs.

Keywords: Family practice, Incidence, Medical records, Population characteristics, Public health, Prevalence

BACKGROUND

Policy makers need valid epidemiological information about the incidence and prevalence rates of diseases in the population to formulate public health policy. Every four years, the Dutch Public Health Status and Forecasts Report presents an overview of the population's health status using key public health indicators such as (healthy) life expectancy, morbidity rates and health determinants.[1,2] In this report general practice based data are used to estimate the population's morbidity in terms of incidence and prevalence rates of many diseases.

Using data generated by general practice registration networks (GPRNs) to estimate morbidity has many advantages, especially in countries with a strong primary care system, like the United Kingdom and the Netherlands.[3-5] In these countries, all non-institutionalized residents are listed with a single general practitioner (GP), which makes a precise determination of the population at risk possible.

GPRNs put a lot of effort in building a reliable database. GPs, who belong to the same GPRN, are expected to use uniform recording methods and classification systems to record diseases. Furthermore, GPRNs systematically check the data to assure quality. Still, GPRNs differ from each other on several aspects. For example, there are GPRNs that include all morbidity presented in general practice, 'episode based' registries, while others only record chronic or very serious conditions into their database, also called 'problem based' registries.[4]

In a previous paper, we identified possible explanations for differences in morbidity rates between Dutch GPRNs and categorized them into four types of factors, health care system, methodology, practice/practitioner characteristics and patient characteristics. Until now, the contribution and mechanisms of these factors on the differences in morbidity estimation between GPRNs are not fully understood.[3,4] To improve the usability of GPRN data for morbidity estimations of the total national population these aspects need to be investigated.

In this paper we investigate the effect of differences in patient characteristics on variation in morbidity estimations between GPRNs. Age, gender, socio-economic status (SES), urbanization level and ethnicity affect the probability to be diagnosed with a certain disease. For example, 65 percent of the people in low socio-economic class is chronically ill compared to nearly 40 percent of the people in the highest socio-economic class.[1] There is reason to believe that the distribution of population characteristics varies between GPRNs, because some networks only operate in urban areas, while others operate in both urban and rural areas.[4] Furthermore, most networks operate in a specific region, while immigrants are not equally spread across the Netherlands.[6]

Before investigating the effect of socio-demographic characteristics on the variation in morbidity between GPRNs, we studied the variation between networks and practices. We assume that for diseases with more ambiguous diagnostic criteria (e.g. depression) the variation between networks and between practices is larger than for diseases with clear diagnostic criteria (e.g. diabetes mellitus).[7] For diseases with disease-free periods (e.g. dermatitis, depression), we expect more variation in prevalence rates than in incidence rates.[8,9] These differences result from difficulties in

determining the ending of an episode in the registration. An episode starts when a GP records information about a patient's health, from contact with the patient or from information about the patient's condition from other health care providers, in the patient's medical record. On the other hand, a GP does not receive information when a disorder is cured.[10,11]

In summary, the goal of this paper is to study the variation between general practices and networks in incidence and prevalence rates of a selection of diseases. To gain more insight in possible explanations for these differences in morbidity rates, we investigate the influence of population characteristics. We hypothesize that adjusting for differences in age, gender, SES, urbanization level, and ethnicity between networks will reduce the variation between networks and therefore partly explain the differences in morbidity estimations between GPRNs.

METHODS

Databases

We used 'episode based' data, which include information about all contacts for a specific health problem of an individual patient. Episodes are defined as the period between the first presentation of a health problem in general practice until the last recorded contact for the same health problem or disease. Episodes contain the coded information about diagnosis, referrals, interventions and prescribed medication.[10]

We used data from six Dutch GPRNs, who were able to supply episode based data; the Continuous Morbidity Registration Nijmegen (CMR-N), the General Practice Network Academic Medical Centre (HAGnetAMC), the Netherlands Information Network of General Practice (LINH), the Registration Network of General Practitioners Associated with Leiden University (RNUH-Leo), the Study of Medical Information and Lifestyle in Eindhoven (SMILE) and the Transition project (Trans). Details of these GPRNs and other Dutch databases can be found elsewhere.[4]

Using the data

We performed an observational study without any interventions. In the Netherlands, no approval is necessary from an ethical committee for analyzing data from general practice registration networks. The data are not openly available, permission to use the data is granted by RNUH-LEO, SMILE, Transition project, LINH steering committee, HAG-net-AMC steering committee and the chair of CMR-N.

Selection of diseases

We selected the diseases on the basis of three criteria. First, the expected occurrence of the disorder in the general Dutch population should be at least 3 per 1000 per year, with a preference for the more common diseases.[7] Second, we aimed to represent all ICD classification chapters to obtain a broad spectrum of diseases (chronic and acute illnesses, psychological and somatic diagnoses, illnesses of different organ systems). Third, we selected a variation of diseases to include a variation of diseases

which mainly occur in specific groups of people (young, old people, women, men). Twelve diseases were selected; gastrointestinal tract infections, diabetes mellitus, depression, anxiety disorders, stroke, coronary heart disease (CHD), chronic obstructive pulmonary disease (COPD), asthma, urinary tract infection, dermatitis, osteoarthritis and neck and back problems. Shingles or herpes zoster was added as 13th disease because of its consistent occurrence in the population. Fleming and colleagues demonstrated that the incidence rates of herpes zoster can be used as an indicator of accurate population estimates and it might be used as an indicator of recording quality.[12]

Incidence and prevalence rates

In general, GPs record diagnoses according to the International Classification of Primary Care (ICPC),[13] only one GPRN uses the so-called E-list codes.[14,15] To obtain comparable morbidity rates some codes were combined to determine incidence and prevalence rates. Different codes for neck and back problems are, for example, combined into one disease category. The GPs of all GPRNs are trained to use the classification system properly.

In this study, we used data recorded in 2007. To determine incidence rates we counted all patients with a new episode of a certain disease in the period from January 1 2007 to December 31 2007 per 1000 listed patients. The incidence of chronic diseases represents the number of patients that have been diagnosed with the disease for the first time. The incidence figures of acute or recurring illnesses represent the number of patients that at least had one new episode of the disease in 2007. Prevalence rates were calculated by counting the number of patients with a new or an existing episode of a specific disease in 2007 per 1000 listed patients. Incidence rates were calculated for all thirteen diseases; prevalence rates were only calculated for the 10 chronic or recurring diseases. The epidemiological denominator was measured by counting all listed patients adjusted for the number of days a person was registered in the general practice (in case of moving from or to the practice, death or new-borns) in 2007. One GPRN (HAG-net-AMC) had only prevalence data available.

Socio-demographic characteristics

We analyzed the effect of age, gender, SES, urbanization level and ethnicity. Age (in years) and gender were derived from the central database of the GPRN. SES, urbanization level and ethnicity were determined by proxy using 4-digit postal codes of the patients' home address (the population size is about 4000 per postal code area).[16] The SES score was developed by Knol and colleagues, who estimated SES using principal-component analysis on the basis of different factors indicating socio-economic position, such as average income per household, percentage low income households, percentage unemployed, and percentage households with a low educational level. These indicators are commonly used to determine SES and contribute to a fair estimation of the SES of the population a particular area. The results of this analysis were available on the website of the Netherlands Institute for Social Research (SCP).[17] The values were divided into quintiles, but to retain the power in our analyses we recoded SES into three categories (1-2 = high, 3 = medium, 4-5 = low SES). Following common practice, urbanization level and ethnicity were derived from Statistics Netherlands.[16] Urbanization level was analyzed in three categories; 'very urban', 'urban'

and 'rural', based on the total number of addresses in one postal code. Ethnicity was based on the percentage non-western immigrants in a postal code area according to the definition of Statistics Netherlands. To be classified as a non-western immigrant a person or at least one of his/her parents must be born in a non-western country (Turkey, all countries in Africa, countries in Asia or the South-America, except of Netherlands East Indies and Japan). We distinguished four categories: people living in neighbourhoods with almost no (0 < 10%), some (10<50%), many (50<70%) and most (≥70%) persons from non-western origin. This represents the probability that a person is from non-western origin.

Analyses

Descriptive analyses were applied to get insight into the frequency and distribution of socio-demographic characteristics of the listed patient population of GPRNs. To explore the differences in morbidity rate estimates between GPRNs multilevel logistic regression analysis was used, distinguishing three levels (patient, practice, and network). We used random intercepts on network and practice level to determine the unexplained variation between GPRNs and practices. The differences in morbidity estimations between GPRNs were analyzed by calculating the corresponding median odds ratio (MOR) and 95% confidence intervals. MOR quantifies the variation between clusters by comparing two 'identical' persons from two randomly chosen, but different clusters. MOR expresses the heterogeneity on an odds ratio scale between clusters and represents the median increased risk. Consequently MOR can never be smaller than one. A cluster consists of all patients belonging to the same practice or network, respectively. In multilevel logistic regression analysis, MOR can be calculated for the network and practice level. In this paper, MOR implies that between two randomly chosen practices or networks, the risk of being diagnosed with a disease (i.e. diabetes mellitus) is x times higher in the randomly chosen network or practice with the highest occurrence rate compared to the risk of being diagnosed with that disease in the other randomly chosen network or practice with the lowest occurrence rate.[18,19]

We analyzed the effect of socio-demographic characteristics in three steps. The first step consisted of analyzing the variation in an empty model (model 0), where no socio-demographic characteristics were taken into account. In the second step, the variation between networks and practices was adjusted for age and gender (model 1) and in the third step SES, level of urbanization and ethnicity were also considered (model 2). All analyses were carried out using SAS version 9.2.

RESULTS

Socio-demographic characteristics

The total study population consisted of 487,516 persons in 109 practices with a mean age of 38.5 years and almost fifty percent males (49.0%), see Table 1. The distribution of age and gender was comparable between GPRNs, the proportion of males ranged from 47.4 to 49.4 percent and the age differences between GPRNs varied in the age group under 20 years from 22.9 to 26.3 percent

and the age group over 65 years from 11.4 to 17.5 percent. The distribution of SES, urbanization level and ethnicity was more diverse: the relative size of the low SES group ranged from 10.6 to 79.7 percent and some GPRNs operated almost exclusively in 'very urban' areas (highest rate 86.0%) while others operated mainly in 'rural' areas (highest rate 71.8%). Less than 0.5 percent of the population of CMR-N, RNUH-LEO, SMILE and Trans lived in neighbourhoods with 50% or more non-western immigrants.

Table 1 Socio-demographic characteristics of General Practice Registration Networks

				Age			SES distribution			Urbanization			Ethnicity			
	patients	practices	% male	0<20	20<65	65+	low	medium	high	very urban	urban	rural	0<10	10<50	50<70	≥70
CMR-N	10409	3	47.8	26.3	60.2	13.5	16.4	24.2	59.4	24.5	3.7	71.8	92.1	7.9	0.0	0.0
HAGnetAMC	43930	7	47.4	24.7	63.9	11.4	79.7	13.0	7.3	86.0	0.4	13.5	13.7	9.8	60.3	16.3
LINH	327551	81	49.4	24.0	61.8	14.1	48.4	24.9	26.7	38.8	16.2	45.1	68.4	25.9	3.7	2.1
RNUH-LEO	34835	4	48.9	24.3	63.6	12.1	10.6	18.7	70.7	34.1	34.8	31.0	71.5	28.5	0.0	0.0
Smile	56799	9	48.5	22.9	59.6	17.5	70.1	7.4	22.5	66.7	22.0	11.4	17.0	83.0	0.0	0.0
Trans	13992	5	48.5	23.9	60.2	15.9	25.2	29.8	45.0	50.1	9.4	40.5	42.2	57.4	0.2	0.1

[#] NW immigrants = percentage of the population which live in neighbourhoods with almost no (0<10%), some (10<50%), many (50<70%) or most (≥70%) persons from non-western origin

Differences in morbidity estimations between GPRNs

Table 2 shows the included ICPC-1 codes of the diseases and disorders under study. The range of the incidence and prevalence rates between GPRNs is large (Table 2). For example, the estimated incidence rates of depression range from 4.4 to 14.2 per 1000 in 2007. We observed these relatively large differences in most diseases.

This is also illustrated by the MOR. The results of model 0 illustrate the variations without adjusting for any socio-demographic covariates. If we consider the incidence rates of depression again, a MOR of 1.49 (1.14-3.04) is shown between networks and 1.40 (1.29-1.52) between practices. This implies that in two randomly chosen GPRNs, the risk of being diagnosed with depression is "on average" about 1.5 times higher in the GPRN with the highest incidence rate than in the GPRN with the lowest incidence rate.

Statistical significant differences between GPRNs were found for most other diseases. There were some exceptions. The incidence rates of herpes zoster showed no significant differences between networks ($MOR_{network}$ = 1.08 (1.00-1.34) p-value = 0.19), as did the incidence rates of diabetes mellitus, coronary heart disease, urinary tract infection and osteoarthritis.

In general, the amount of variation between practices is larger than between networks. This is visible in incidence rates of 10 out of 13 diseases and in prevalence rates of 6 out of 10 diseases. An evident example is diabetes mellitus, where the morbidity rate estimates of diabetes mellitus show relatively small differences between networks (incidence rates $MOR_{network}$ = 1.00 (1.00-1.37) and

prevalence rates $MOR_{networks}$ = 1.20 (1.08-1.61) but the variations between practices are relatively large (incidence rates $MOR_{practice}$ = 1.59 (1.44-1.77) and prevalence rates $MOR_{practice}$ = 1.49 (1.43-1.53)).

Looking at differences between networks, relatively large differences (MOR > 1.40) were seen in the incidence rates of gastrointestinal tract infections, depression and anxiety disorders and the prevalence rates of depression, anxiety disorders, stroke, CHD, dermatitis, osteoarthritis and neck and back problems. Overall, the variation in incidence rates is smaller than the variation in prevalence rates between networks as well as between practices.

Table 2 Variations in morbidity estimations of 13 diseases; incidence rates, prevalence rates and median odds ratios

		Incidence			Prevalence		
			MOR *(95%CI)*			MOR *(95%CI)*	
Diseases	***ICPC1 Codes***	***Range (per 1000)***	**Network**	**Practice**	***Range (per 1000)***	**Network**	**Practice**
Gastrointestinal tract infection	D70, D73	10.4-28.2	**1.47** 1.22-2.75	**1.54** 1.40-1.68	*n/a*	*n/a*	*n/a*
Diabetes mellitus	T90	3.3-4.6	1.00 1.00-1.37	**1.59** 1.44-1.77	30.9-57.2	**1.20** 1.08-1.61	**1.49** 1.43-1.53
Depression	P03, P76	4.4-14.2	**1.49** 1.14-3.04	**1.40** 1.29-1.52	21.6-64.4	**1.58** 1.27-3.05	**1.70** 1.61-1.79
Anxiety disorder	P01, P74	2.6-14.6	**1.71** 1.22-4.26	**1.52** 1.39-1.67	11.3-44.4	**1.64** 1.29-3.32	**1.73** 1.65-1.82
Stroke	K89, K90	2.3-5.9	**1.38** 1.10-2.49	**1.47** 1.33-1.65	3.3-47.2	**1.85** 1.42-4.28	**1.78** 1.74-1.88
CHD	K74, K75, K76	2.8-5.4	1.00 1.00-1.86	**1.71** 1.51-195	9.7-47.2	**1.78** 1.35-4.57	**1.86** 1.75-1.97
COPD	R91, R95	1.3-3.9	**1.40** 1.09-2.87	**1.54** 1.39-1.73	12.1-33.0	**1.35** 1.14-2.14	**1.65** 1.57-1.73
Asthma	R96	2.9-6.2	**1.37** 1.10-2.61	**1.70** 1.52-1.90	29.2-60.0	**1.29** 1.13-1.91	**1.59** 1.52-1.66
Urinary tract infection	U70, U71, U72	29.4-46.1	1.19 1.00-1.69	**1.35** 1.27-1.49	*n/a*	*n/a*	*n/a*
Dermatitis	S88, S87	16.9-57.0	**1.20** 1.05-1.70	**1.28** 1.21-1.38	27.9-161.2	**1.76** 1.39-3.72	**1.56** 1.49-1.62
Osteoarthritis	L89, L90, L91	5.4-9.7	1.20 1.00-1.87	**1.51** 1.37-1.65	12.3-61.2	**1.86** 1.43-4.32	**1.62** 1.54-1.70
Neck and back problems	L01, L02, L03, L83, L84, L86	42.3-78.9	**1.28** 1.13-1.94	**1.24** 1.19-1.33	29.8-302.5	**2.26** 1.63-6.44	**1.39** 1.35-1.43
Herpes zoster	S70	3.5-4.5	1.08 1.00-1.34	**1.23** 1.11-1.36	*n/a*	*n/a*	*n/a*

Note: **Bold** variation between network versus practices is significant (p<0.05).

Table 3 Variation in Incidence data in MOR adjusted for population characteristics

	Model 0		**Model 1**		**Model 2**	
	-		***Age, gender***		***Age, gender, SES, ethnicity and urbanization level***	
MOR *(95%CI)*	**Network**	**Practice**	**Network**	**Practice**	**Network**	**Practice**
Gastrointestinal tract infection	**1.47** 1.22-2.75	**1.54** 1.40-1.68	**1.45** 1.22-2.66	**1.51** 1.38-1.64	**1.40** 1.17-2.50	**1.47** 1.36-1.61
Diabetes mellitus	1.00 1.00-1.37	**1.59** 1.44-1.77	1.00 1.00-1.42	**1.62** 1.46-1.81	1.00 1.00-1.49	**1.67** 1.48-1.87
Depression	**1.49** 1.14-3.04	**1.40** 1.29-1.52	**1.48** 1.12-3.02	**1.41** 1.31-1.54	**1.40** 1.00-2.77	**1.41** 1.30-1.55
Anxiety disorder	**1.71** 1.22-4.26	**1.52** 1.39-1.67	**1.70** 1.21-4.21	**1.51** 1.38-1.66	**1.63** 1.18-3.86	**1.52** 1.39-1.67
Stroke	**1.38** 1.10-2.49	**1.47** 1.33-1.65	**1.27** 1.03-2.08	**1.40** 1.30-1.56	1.24 1.00-2.02	**1.38** 1.29-1.40
CHD	1.00 1.00-1.86	**1.71** 1.51-195	1.00 1.00-1.50	**1.66** 1.46-1.89	*	*
COPD	**1.40** 1.09-2.87	**1.54** 1.39-1.73	**1.40** 1.12-2.76	**1.49** 1.35-166	**1.44** 1.17-2.78	**1.42** 1.30-1.62
Asthma	**1.37** 1.10-2.61	**1.70** 1.52-1.90	**1.38** 1.11-2.66	**1.69** 1.51-1.88	**1.43** 1.14-2.77	**1.70** 1.52-1.91
Urinary tract infection	1.19 1.00-1.69	**1.35** 1.27-1.49	**1.19** 1.00-1.70	**1.35** 1.27-1.44	**1.19** 1.00-1.68	**1.33** 1.25-1.42
Dermatitis	**1.20** 1.05-1.70	**1.28** 1.21-1.38	**1.19** 1.04-1.68	**1.27** 1.21-1.38	**1.19** 1.00-1.67	**1.26** 1.20-1.36
Osteoarthritis	1.20 1.00-1.87	**1.51** 1.37-1.65	*	*	*	*
Neck and back problems	**1.28** 1.13-1.94	**1.24** 1.19-1.33	**1.28** 1.13-1.94	**1.25** 1.19-1.35	**1.22** 1.07-1.74	**1.22** 1.17-1.31
Herpes zoster	1.08 1.00-1.34	**1.23** 1.11-1.36	**1.07** **1.00-1.29**	**1.17** 1.00-1.31	1.00 1.00-1.26	**1.20** 1.06-1.34

Note: **Bold** variation between network or variation between practices is significant (p<0.05). * analyses did not converge

Socio-demographic characteristics and differences in morbidity

The socio-demographic characteristics, age and gender contributed significantly to the morbidity estimates of all diseases (except gender in COPD). SES, ethnicity and urbanization level showed only a significant contribution to morbidity rate estimates for a part of the diseases under study (results not shown). Even though differences in the distribution of socio-demographic characteristics are apparent (Table 1) we observe only small changes in variation in morbidity estimates between GPRNs (Table 3 and 4). In most diseases the MOR seems to decrease after adjustment for population characteristics, although for some diseases, the MOR even increased. For example, the variations between GPRNs in incidence rates of depression with and without adjusting for socio-demographic characteristics, expressed in MOR, are 1.49 (1.14-3.04) (no adjustments), 1.48 (1.12-3.02) (age and gender) and 1.40 (1.00-2.77) (adjusted for age, gender, SES, ethnicity, and urbanization level). Overall, accounting for socio-demographic characteristics did not explain the variation between GPRNs or practices.

DISCUSSION

Morbidity estimates can be derived from routine data collected in general practice. A setback for using these data for public health reporting is that morbidity estimates vary largely between different general practice registration networks (GPRNs). In this study we quantified these differences and studied the effect of socio-demographic characteristics of the population covered by the different GPRNs on the variations in 'episode based' morbidity data.

Summary of main findings

There are large differences in morbidity rate estimates between GPRNs and these differences are more apparent for prevalence than for incidence rates. The risk of being diagnosed with a particular disease depends on the GPRN or general practice a patient belongs to. An exception is, for example, the incidence of diabetes mellitus which shows almost no variation. Differences in socio-demographic characteristics could not explain the variation in morbidity estimations between GPRNs.

Table 4 Variation in Prevalence data in MOR adjusted for population characteristics

	Model 0		Model 1		Model 2	
	-		*Age, gender*		*Age, gender, SES, ethnicity and urbanization level*	
MOR ***(95%CI)***	**Network**	**Practice**	**Network**	**Practice**	**Network**	**Practice**
Diabetes mellitus	**1.20** 1.08-1.61	**1.49** 1.43-1.53	**1.20** 1.07-1.58	**1.48** 1.43-1.53	**1.13** 1.04-1.39	**1.40** 1.35-1.44
Depression	**1.58** 1.27-3.05	**1.70** 1.61-1.79	**1.58** 1.27-3.06	**1.72** 1.64-1.81	**1.53** 1.24-2.84	**1.70** 1.61-1.78
Anxiety disorder	**1.64** 1.29-3.32	**1.73** 1.65-1.82	**1.64** 1.29-3.30	**1.74** 1.65-1.83	**1.53** 1.22-2.87	**1.73** 1.64-1.83
Stroke	**1.85** 1.42-4.28	**1.78** 1.74-1.88	**1.81** 1.40-4.08	**1.73** 1.70-1.83	**1.82** 1.40-4.20	**1.72** 1.69-1.83
CHD	**1.78** 1.35-4.57	**1.86** 1.75-1.97	**1.72** 1.33-4.20	**1.85** 1.82-1.96	**1.60** 1.27-3.55	**1.85** 1.82-1.96
COPD	**1.35** 1.14-2.14	**1.65** 1.57-1.73	**1.33** 1.13-2.08	**1.63** 1.61-1.70	**1.30** 1.11-1.95	**1.60** 1.58-1.68
Asthma	**1.29** 1.13-1.91	**1.59** 1.52-1.66	**1.30** 1.13-1.93	**1.58** 1.52-1.65	**1.24** 1.08-1.73	**1.61** 1.54-1.68
Dermatitis	**1.76** 1.39-3.72	**1.56** 1.49-1.62	**1.76** 1.39-3.73	**1.56** 1.50-1.63	**1.79** 1.40-3.89	**1.58** 1.51-1.64
Osteoarthritis	**1.86** 1.43-4.32	**1.62** 1.54-1.70	**1.89** 1.45-4.47	**1.59** 1.57-1.66	**1.88** 1.44-4.37	**1.58** 1.56-1.66
Neck and back problems	**2.26** 1.63-6.44	**1.39** 1.35-1.43	**2.33** 1.66-6.94	**1.42** 1.38-1.47	**2.39** 1.68-7.32	**1.41** 1.37-1.45

Note: **Bold** variation between network or variation between practices is significant (p<0.05)

Differences between networks and between practices

Hardly any variations between GPRNs are observed in the incidence rates of diabetes mellitus, CHD, urinary tract infections, osteoarthritis and herpes zoster. Diabetes is a disease which can be clearly diagnosed. The same is true for urinary tract infection, osteoarthritis and herpes zoster, which are often painful and therefore patients are likely to seek medical care. For patients with CHD it is important to receive medical care and therefore these patients are nearly always known by the GP.

We expected differences between GPRNs and practices in morbidity estimates to be larger in diseases with more ambiguous diagnostic criteria.[7] In accordance with this expectation, large differences were seen in depression, anxiety disorders and gastrointestinal tract infections, where determination of these disorders depends highly on the presentation of the complaints to the GP.

Furthermore, large differences were expected in the prevalence rates of recurring diseases. Prevalence is influenced by the routine of closing episodes of diseases in the registration when the recurrence of the condition is over.[3] The large variations found in the prevalence rates of depression, dermatitis and neck and back problems might be explained by differences in these routines between GPRNs.

Interestingly, we expected large differences in diseases for which people receive little medical care, but this was only observed in the prevalence of osteoarthritis. We observed hardly any differences in incidence rates, which suggest that GPs see and diagnose relatively the same number of patients with osteoarthritis. This may also be true for neck and back problems. The large differences could be explained by different operational definitions and recording rules of prevalent cases in the different GPRNs. Defining a prevalent case in "episode based" data can be done in two ways: 1) a case is prevalent only when the patient has had at least one GP-contact for that disease in the year of interest or 2) all known cases with a previously recorded diagnoses for that disease, count as prevalent cases, irrespective whether a contact for that disease took place in the observation year. Osteoarthritis is a chronic disease, but since health care cannot always provide effective treatment patients do not necessarily contact their GP each year. These differences in recording rules may explain some of the variation in prevalence rates between GPRNs.

For most diseases differences are larger between practices than between GPRNs. This is apparent in the incidence rates of diabetes mellitus, even though diabetes mellitus has clear diagnostic criteria and results are adjusted for socio-demographic characteristics of the patients. This can possibly be explained by coding qualities of practices within networks or differences in practice characteristics, but this was not investigated in this research. In this context it is also interesting to investigate the differences between strict and more interpretable recording rules on variation between practices.

Influence of population characteristics

Although age and gender contribute significantly to the determination of morbidity, differences between GPRNs and between practices do not change after adjustment for these variables. This finding seems contradictive, but there are just small differences in age and gender distribution between GPRNs and therefore only small changes are possible.

The influence of SES, ethnicity and urbanization level is also limited, despite the large differences in distribution between GPRNs. We believe this to be the case due to little power, because of the small numbers of patients diagnosed with a disorder in comparison to the 'healthy' people. Furthermore if the socio-demographic characteristics significantly contribute to an improved morbidity estimation, as for example SES and ethnicity in back and neck problems (results not shown), this effect is too small to actually change MOR.

Strengths and limitations of this study

To our knowledge, this is the first study to investigate the influence of socio-demographic characteristics on the variation of morbidity estimates between 'episode based' GPRNs. The distribution of age and gender in the different network populations corresponds reasonably well to the Dutch general population.

The differences in ethnicity and urbanization level are much larger between networks, which is caused by the fact that most networks operate regionally and the distribution of these characteristics is not equally distributed between regions in the Netherlands. Therefore we think adjusting for these characteristic is essential. Some GPRNs show an extreme distribution on some of the socio-demographic characteristics as, for example; more than 97% population lives in very urban areas. Reanalysis without this GPRN did not lead to changes: some variations slightly increased, some decreased, and still hardly any changes were seen after adjusting for socio-demographic characteristics (results not shown).

To investigate the effect of socio-demographic characteristics, we adjusted for the differences in population composition between GPRNs. However, direct measures of SES and ethnicity were not available, and we had to rely on proxy measures. This may have led to an underestimation of the effects of SES and ethnicity because of these less accurate estimates. Overall, the relations found seem to be legitimate. For example, low SES was related to higher morbidity rates of diabetes mellitus and in COPD high SES was related to lower morbidity rates (results not shown).[20] Although direct measures are more precise this could not explain that some variations even increase. Therefore we assume our conclusion, that socio-demographic characteristics do not explain differences between GPRNs, to be valid.

The differences in incidence estimations of herpes zoster between GPRNs are small and within the range seen in other research.[12] As the crude figures for herpes zoster show no significant variation between networks (MORnetwork = 1.08 (1.00-1.34)), we can conclude that the populations used are sufficient. It might even indicate a good recording quality of the GPRNs.[12]

We only used 'episode based' data to rule out the differences due to different types of data. We have data of eight Dutch GPRNs, four networks only have 'episode based' morbidity data, two have 'problem based' data and two have both. Such a low number of GPRNs makes it impossible to include data type in the multilevel analyses. Other Dutch GPRNs did not want to participate or were not able to deliver their data on time. Dutch GPRNs differ from each other, but the distribution of

the population characteristics in different GPRNs was broad and therefore we think considering other GPRNs would not have changed our conclusion.

CONCLUSIONS

In a previous paper, we identified factors which may be responsible for the differences in morbidity between general practices and registration networks. Current research showed that one of the factors, the characteristics of the patient population, could not explain these differences. Understanding the differences between GPRNs and practices is a first step to come to the most valid and reliable estimate for the morbidity in the general population.

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SUPPLEMENT POPULATION CHARACTERISTICS

Rectification of the analysis of "the influence of population characteristics on variation in general practice-based morbidity estimations.

Databases

The intention was to use only 'episode based' data. By mistake, the General Practice Network Academic Medical Centre (HAGnetAMC) was used, but is a so-called "problem-list" registry. The Academic Network of General Practitioners of VU Medical Centre (ANH Vumc) should have been included. This network also only includes reliable prevalence figures. Re-analysis showed only small differences, the conclusion and most important findings still remain the same.

Using the data

Permission to use and publish their data was granted by ANH Vumc.

In the next section we will answer for the differences in the analysis and results. We will only reflect on the results that appeared to be different after re-analysis.

Socio-demographic characteristics

The non-western immigrants were analysed for only two categories; people living in neighbourhoods with almost no (0<50%) or most (70%) persons from non-western origin, to increase the discriminative analysis. This represents the probability that a person is from non-western origin.

Table S1 Socio-demographic characteristics of General Practice Registration Networks

				Age distribution			SES distribution			Urbanization			Ethnicity	
	patients	practices	% male	0<20	20<65	65+	low	medium	high	very urban	urban	rural	0<50	≥50
CMR-N	10409	3	47.8	26.3	60.2	13.5	16.4	24.2	59.4	24.5	3.7	71.8	100.0	0.0
ANH VUmc	36684	9	46.8	21.5	64.6	13.9	44.8	6.4	48.8	97.8	1.3	0.9	88.7	12.3
LINH	327551	81	49.4	24.0	61.8	14.1	48.4	24.9	26.7	38.8	16.2	45.1	94.3	5.8
RNUH-LEO	34835	4	48.9	24.3	63.6	12.1	10.6	18.7	70.7	34.1	34.8	31.0	100.0	0.0
Smile	56799	9	48.5	22.9	59.6	17.5	70.1	7.4	22.5	66.7	22.0	11.4	100.0	0.0
Trans	13992	5	48.5	23.9	60.2	15.9	25.2	29.8	45.0	50.1	9.4	40.5	99.6	0.3

[#] NW immigrants = percentage of the population which live in neighbourhoods with almost no (0<50%) or most (≥50%) persons from non-western origin

The total population was smaller (about 7000 persons), but two more practices were included. The distribution of age and gender was rather similar. ANH VUmc is has more patients living in 'very urban' areas (ANH VUmc=97.8% versus HAGnetAMC=86.0%), in higher SES areas (lowSES ANH VUmc=44.8% versus HAGnetAMC=79.7%), and in neighourhoods with higher percentages of people of non-western origin (in the category 0<50%; ANH VUmc=88.7 versus HAGnetAMC=23.5%).

Differences in morbidity estimations between GPRNs

Only re-analysis of the prevalence figures was necessary. Changes in variation of prevalence rates were mainly seen in the variation between networks. An increase of variation was seen in diabetes mellitus, stroke, coronary heart disease (CHD), chronic obstructive pulmonary disease (COPD), and Asthma. A decrease of variation was found in anxiety disorders, dermatitis, and neck and back problems. This last decrease is comprehensible, because HAGnetAMC only included disorders on the problem list, and recurring diseases are less likely to appear on the problem list (to GPs' best judgment)

In 5 out of 10 diseases, the variance was larger between general practices than between networks. Looking at differences between networks, relatively large differences (MOR > 1.40) was also seen in COPD (re-analysis MOR 1.46). The overall conclusion remained the same; accounting for socio-demographic characteristics did not explain the variation between GPRNs or practices.

Table S2 Variations in morbidity estimations of 10 prevalent diseases after re-analysis (including ANH VUmc and excluding HAGnetAMC)

			Prevalence			
			MOR *(95%CI)*			
Diseases	*ICPC-1 Codes*	*Changed range of prevalence (per 1000)*	Network including HAGnetAMC	Network including ANH VUmc	Practice Including HAGnetAMC	Practice Including ANH VUmc
Diabetes mellitus	T90		**1.20** 1.08-1.61	**1.29** 1.09-1.91	**1.49** 1.43-1.53	**1.54** 1.48-1.60
Depression	P03, P76		**1.58** 1.27-3.05	**1.57** 1.28-3.00	**1.70** 1.61-1.79	**1.66** 1.59-1.74
Anxiety disorder	P01, P74	17.4-44.4	**1.64** 1.29-3.32	**1.51** 1.22-2.76	**1.73** 1.65-1.82	**1.71** 1.63-1.79
Stroke	K89, K90		**1.85** 1.42-4.28	**2.14** 1.55-5.98	**1.78** 1.74-1.88	**1.78** 1.75-1.88
CHD	K74, K75, K76	5.1-47.2	**1.78** 1.35-4.57	**2.25** 1.60-6.70	**1.86** 1.75-1.97	**1.86** 1.75-1.97
COPD	R91, R95	10.8-33.0	**1.35** 1.14-2.14	**1.46** 1.20-2.56	**1.65** 1.57-1.73	**1.70** 1.61-1.78
Asthma	R96	25.3-60.0	**1.29** 1.13-1.91	**1.38** 1.15-2.22	**1.59** 1.52-1.66	**1.63** 1.56-1.70
Dermatitis	S88, S87	51.2-161.2	**1.76** 1.39-3.72	**1.58** 1.30-2.92	**1.56** 1.49-1.62	**1.55** 1.49-1.62
Osteoarthritis	L89, L90, L91		**1.86** 1.43-4.32	**1.91** 1.46-4.55	**1.62** 1.54-1.70	**1.60** 1.53-1.67
Neck and back problems	L01, L02, L03, L83, L84, L86	79.7-302.5	**2.26** 1.63-6.44	**1.89** 1.46-4.29	**1.39** 1.35-1.43	**1.36** 1.33-1.40

Note: **Bold** variation between network versus practices is significant (p<0.05).

Table S3 Variation in Prevalence data in MOR adjusted for population characteristics

	Model 0		Model 1		Model 2	
	-		*Age, gender*		*Age, gender, SES, ethnicity and urbanization level*	
MOR *(95%CI)*	**Network**	**Practice**	**Network**	**Practice**	**Network**	**Practice**
Diabetes mellitus	**1.29** 1.09-1.91	**1.54** 1.48-1.60	**1.31** 1.10-1.96	**1.56** 1.50-1.62	**1.32** 1.12-1.98	**1.50** 1.45-1.56
Depression	**1.57** 1.28-3.00	**1.66** 1.59-1.74	**1.56** 1.27-2.97	**1.70** 1.62-1.78	**1.52** 1.24-2.81	**1.69** 1.61-1.78
Anxiety disorder	**1.51** 1.22-2.76	**1.71** 1.63-1.79	**1.50** 1.21-2.71	**1.73** 1.65-1.82	**1.46** 1.18-2.58	**1.72** 1.64-1.81
Stroke	**2.14** 1.55-5.98	**1.78** 1.75-1.88	**2.17** 1.57-6.11	**1.73** 1.70-1.83	**2.17** 1.56-6.13	**1.74** 1.71-1.85
CHD	**2.25** 1.60-6.70	**1.86** 1.75-1.97	**2.31** 1.62-7.10	**1.86** 1.84-1.97	**2.31** 1.62-7.12	**1.88** 1.77-1.99
COPD	**1.46** 1.20-2.56	**1.70** 1.61-1.78	**1.47** 1.21-2.59	**1.68** 1.66-1.76	**1.45** 1.19-2.50	**1.66** 1.58-1.74
Asthma	**1.38** 1.15-2.22	**1.63** 1.56-1.70	**1.38** 1.16-2.23	**1.62** 1.55-1.69	**1.36** 1.13-2.17	**1.65** 1.58-1.73
Dermatitis	**1.58** 1.30-2.92	**1.55** 1.49-1.62	**1.58** 1.30-2.93	**1.55** 1.49-1.61	**1.56** 1.29-2.85	**1.57** 1.50-1.63
Osteoarthritis	**1.91** 1.46-4.55	**1.60** 1.53-1.67	**2.00** 1.50-5.01	**1.59** 1.57-1.66	**1.93** 1.47-4.66	**1.59** 1.51-1.66
Neck and back problems	**1.89** 1.46-4.29	**1.36** 1.33-1.40	**1.92** 1.48-4.50	**1.41** 1.37-1.45	**1.89** 1.46-4.34	**1.40** 1.36-1.48

Note: **Bold** variation between network or variation between practices is significant (p<0.05)

CHAPTER 4

Do practice characteristics explain differences in morbidity estimates between electronic health record based general practice registration networks?

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ABSTRACT

Background: General practice based registration networks (GPRNs) provide information on population health derived from electronic health records (EHR). Morbidity estimates from different GPRNs reveal considerable, unexplained differences. Previous research showed that population characteristics could not explain this variation. In this study we investigate the influence of practice characteristics on the variation in incidence and prevalence figures between general practices and between GPRNs.

Methods: We analyzed the influence of eight practice characteristics, such as type of practice, percentage female general practitioners, and employment of a practice nurse, on the variation in morbidity estimates of twelve diseases between six Dutch GPRNs. We used multilevel logistic regression analysis and expressed the variation between practices and GPRNs in median odds ratios (MOR). Furthermore, we analyzed the influence of type of EHR software package and province within one large national GPRN.

Results: Hardly any practice characteristic showed an effect on morbidity estimates. Adjusting for the practice characteristics did also not alter the variation between practices or between GPRNs, as MORs remained stable. The EHR software package 'Medicom' and the province 'Groningen' showed significant effects on the prevalence figures of several diseases, but this hardly diminished the variation between practices.

Conclusion: Practice characteristics do not explain the differences in morbidity estimates between GPRNs.

Keywords: Family practice; Incidence; Electronic medical records; Practice characteristics; Population health; Prevalence

BACKGROUND

In the Netherlands, routinely collected data from general practice based registration networks (GPRNs) are often used to monitor incidence and prevalence of diseases in the general population. The Dutch Public Health Status and Forecasts 2010, for example, showed morbidity figures of several diseases using such data.[1, 2]

This data derived from electronic health records (EHR) in general practice is relevant because the general practitioner (GP) is gatekeeper to secondary care and nearly all inhabitants are enlisted to a single GP (list system). Therefore, GPs have contact with a variety of patients, regarding age, gender, socio-economic status, ethnicity, health problems and disease stage. Furthermore, the list system makes a precise determination of the epidemiological denominator possible.[3, 4]

The estimated incidence and prevalence figures of different diseases show considerable variations between GPRNs. These differences in morbidity estimates are not fully understood, making the interpretation of these figures difficult.[4, 5] The prevalence of osteoarthritis, for example, ranges from 10 to 60 per 1.000 person years between GPRNs. Overall, prevalence figures estimated from GPRNs show more variation than incidence figures.[6]

A generally recognized reason for variation in incidence and prevalence figures is the differences in practice population characteristics. For example, the prevalence of osteoarthritis is higher in older people, leading to a higher estimate of the prevalence of this disease in GPRNs with a higher proportion of elderly people in their practice populations. However, in previous research, we showed that population characteristics could not explain the variation between GPRNs or between general practices.[6]

In earlier research, we identified the GP and practice characteristics as a probable factor of variation between morbidity estimates using GPRN data, also known as inter-doctor variation.[5] Inter-doctor variation is the variation in the frequency of diagnosing health problems between different health care providers, which cannot be explained by the patient characteristics (age, sex, severity of the disease).[7] Research identified different aspects that influence this inter-doctor variation between GPs and practices.[8-10] Examples of such characteristics are availability of health care, organization of care, such as type of practice, employment of a practice nurse and treatment opportunities.[8, 9] There is evidence that different doctor- and practice characteristics, such as experience, workforce, and type of practice, influence medical practice and diagnostic variability. In the second Dutch National Survey of General Practice, urbanization level, type of practice and EHR software package influenced consultation frequency figures.[10]

In this paper we investigate to what extent practice and GP characteristics explain the variation in morbidity estimates between six Dutch GPRNs and related practices.

METHOD

Databases

Six Dutch GPRNs participated in this research; the Continuous Morbidity Registration Nijmegen (CMR-N), the Academic Network of General Practitioners of the VUmc (ANH-VUmc), the Netherlands Information Network of General Practice (LINH)[a], the Registration Network of General Practitioners Associated with Leiden University (RNUH-LEO), the Study of Medical Information and Lifestyle in Eindhoven (SMILE) and the Transition project (Trans). More detailed information of these GPRNs can be found elsewhere.[5] These Dutch GPRNs were selected, because they collect information on all health problems of individual patients. GPRNs which exclusively collect information on chronic, permanent or recurring diseases were left out of this study. *[a] The name of this network changed in 2013 to NIVEL Primary Care Database (NIVEL-PCD).*

Using the data

We performed an observational study without any intervention. In the Netherlands, no approval is necessary from an ethical committee for analyzing data from general practice registration networks. The data are not openly available, permission to use the data is granted by ANH VUmc, RNUH_LEO, SMILE, Transition project, LINH steering committee and the chair of CMR-N.

Selection of diseases

For our analyses we selected twelve health problems: urinary tract infection, gastro-intestinal infection, neck and back problems, eczema, asthma, chronic obstructive pulmonary disease (COPD), osteoarthritis, diabetes mellitus, coronary heart disease (CHD), stroke, depression, and anxiety disorders. The selection of these health problems was based on three criteria: (1) The expected incidence of the specific disorder in the Dutch general practice population was at least 3 per 1000 per year; (2) The total set of diseases represented several ICD chapters (e.g. circulatory system, respiratory system) to obtain a broad spectrum of diseases; (3) The occurrence of incidence and prevalence of included diseases should vary between different patient subgroups (e.g. age, gender).

Incidence and prevalence rates

In this study, we used data of 2007. To determine incidence rates, all patients diagnosed with a new episode of a certain disease between the 1st of January 2007 and the 31st of December 2007 were counted per 1,000 patient years. Prevalence rates were calculated by counting the number of patients with a new or existing episode of a specific disease in 2007 per 1,000 patient years (period prevalence). Incidence rates were calculated for all twelve diseases; prevalence rates were only calculated for the ten chronic or recurring diseases. Five GPRNs record diagnoses according to the International Classification of Primary Care (ICPC), one used the so-called E-list codes.[11-13] When necessary, we combined different classification codes to determine morbidity.[1, 14] For example, to measure depression we used ICPC codes P03 and P76.

Socio-demographic characteristics

This study starts with analyzing the variation in incidence and prevalence figures between GPRNs and general practices adjusted for patient characteristics: age (in years), gender (male versus female), socio-economic status (high-medium-low), urbanization level ('rural', 'urban' and 'large cities') and ethnic origin.[6] The latter three measures were determined by proxy using 4-digit postal codes of the patients' home address (the population size is about 4,000 per postal code area).[15, 16]

Practice characteristics

Within a general practice, patients are generally registered with one specific GP, but most patients are not exclusively treated by that GP. The care in general practice has become more multi-practitioner and multi-disciplinary organized.[3] In most networks, the information of an individual patient cannot be related to an individual doctor and therefore, inter-doctor variation cannot be assessed validly. Instead, we analyzed GP characteristics on practice level.

The practice characteristics used in the analysis are type of practice (one GP = solo, two GPs = duo and three GPs or more = group practice), percentage female GPs, mean years of working experience, employment of a practice nurse (yes/no), EHR software package used in the general practice, province, distance to the nearest out-of-hours service location and distance to the nearest hospital. To be sure all practice characteristics are based on the same type of data we consulted the "Register of General Practitioners" (HAREG) of NIVEL.[17] This database holds information on all practicing GPs and practices in the Netherlands about e.g. gender, age, and working experience. We received the information about the employment of a practice nurse and type of electronic patient record directly from the GPRN. The distances have been calculated with the so-called driving time model of Automotive Navigation Data (AND) in combination with the localizations of the out-of-hours service locations and hospitals, using 4-digit postal codes.[18]

We are interested in the influence of practice characteristics on the variation in morbidity estimates between GPRNs and practices. Therefore, we only used the practices with all population and practice characteristics available. As a consequence, 9 out of 81 practices of LINH, 2 out of 9 practices of ANH VUmc and 1 out of 9 practices of SMILE and 1 out of 5 practices of Trans were excluded from analyses.

Analyses

Descriptive analyses were applied to give an overview of the distribution of the population and practice characteristics. To explore the variation in morbidity estimates between GPRNs and general practices we used multilevel logistic regression analysis with three levels (patient, practice and network). We used random intercepts on network and practice level to determine the unexplained variation between GPRNs and practices. We analyzed the variations in morbidity estimates by calculating the corresponding median odds ratio (MOR) and 95% confidence intervals (95%CI); we also calculated the odds ratios (ORs) of the significant practice characteristics. MOR quantifies the variation between clusters by comparing two 'identical' persons from two randomly chosen, but different clusters. MOR expresses the heterogeneity on an odds ratio scale between clusters and

represents the median increased risk. Consequently MOR can never be smaller than one. MOR has been calculated on practice and network level. In this study, MOR refers to the (statistical) increased risk of being diagnosed with a certain disease between two randomly chosen practices or GPRNs. For example, if MOR is 2.0 the risk of being diagnosed with a specific disease is twice as high for a person in one network compared to an 'identical' person in another network.[19, 20]

First, we analyzed for each disease the variations in morbidity estimates between general practices and GPRNs without taking any practice characteristic into account. Second, we analyzed the influence of six practice characteristics on the variations in morbidity estimates for all diseases in separate models. This results in a total of 154 models (incidence of12 diseases and prevalence of 10 diseases, analyzing the variation in one model without any practice characteristics and 6 models with just one practice characteristic ($22 \times 7 = 154$)). Before we performed multilevel analyses, we checked the correlation between characteristics. A high correlation ($r > 0.70$) was found between the urbanization level of the patient's home address and the distance to the nearest hospital of the general practice. We therefore left urbanization level out of the analyses when measuring the effect of distance to the nearest hospital.

The analyses of type of EHR software package and province could not be performed in a three level analysis, as most GPRNs are located in one province and use only one or two types of EHR software package. The influence of these characteristics was only analysed using LINH data in a two level analysis (patient and practice), since this is the only GPRN located in all provinces and including seven different EHR software packages.[21] All analyses were performed with SAS version 9.2.

RESULTS

The information of a total of 393.102 patients in 97 practices distributed over six networks was analyzed. In total, the participating practices were evenly distributed between solo, duo and group practices. In the different GPNRs, on average 27 to 67 percent of the GPs were female, and the mean number of years of experience of the GPs ranged between 12.3 to 21.3 years. The average distance to the out-of-hours practice or hospital varied between 2.5 and 7 kilometers. As expected, larger distances were seen in more rurally located networks and practices. In general, the mean working experience is higher in networks that exist for a longer period of time. More figures are presented in Table 1.

As described in the methods section, most GPRNs are located in one province and use extracted data from only one type of EHR software package. In this study, LINH is the only nationally distributed network that was processing data from multiple EHR software packages: Acros, Omnihis, Medicom, Microhis, Mira, Promedico and PromedicoASP. Together these software packages cover more that 80% of the market.

Influence of practice characteristics on variation between practices and networks

The variations (in MOR) of the 154 models are presented separately for general practices (Table 2) and GPRNs (Table 3). In only six cases of the 154 models we observed a significant effect of

Table 1 Practice characteristics of six general practice registration networks

	Patients[1] (n)	Practices[1] (n)	Type of practice[2] (n)			% of Practices with POH	% of Female GPs	Mean working experience	Mean distance nearest hospital[3](km)	Mean (range) distance to out-of-hour service location[3](km)
			solo	*duo*	*group*					
ANH VUmc	32 341	7	1	2	4	71.4	62.7	12.7	2.6 (1–4)	2.5 (0–5)
CMR-N	10 291	3	0	1	2	100	41.7	21.3	6.1 (2–9)	7.3 (2–13)
LINH	265 724	72	29	25	18	69.4	27.3	16.0	7.1 (0–22)	6.1 (0–22)
RNUH Leo	25 263	3	0	0	3	100	44.3	20.1	6.8 (3–12)	4.8 (3–6)
Smile	47 528	8	1	2	5	87.5	66.9	12.2	3.7 (0–7)	3.9 (1–7)
Trans	12 154	4	1	2	1	50.0	41.8	19.8	6.4 (2–19)	6.4 (2–19)

[1] Total number can deviate from the network population reported elsewhere because incomplete data are excluded. [2] Based on the number of GPs working in a specific practice. [3] Estimated on basis of the central position of a postal code, which can be deviated from the actual distance.

a practice characteristic on morbidity estimates. Group practices are related to higher estimates of the incidence figures of diabetes mellitus (ORgroup = 1.74) and anxiety (ORgroup = 1.54) as compared to solo practices. The prevalence figures of anxiety are negatively related to the distance between the general practice and the out-of-hours service location (OR = 0.96) and hospital (OR = 0.97), for depression this was only the case for the distance between general practice and the out-of-hours service location (OR = 0.96). Furthermore, the employment of a practice nurse leads to higher estimate of the prevalence of COPD (OR = 1.36).

The MOR, for example, of the variation in incidence between general practices of osteoarthritis is 1.42 (95% CI: 1.30-1.55) and the variation in prevalence is 1.60 (95% CI: 1.46-1.65). This means that the chance of being diagnosed with osteoarthritis is respectively 1.4 times higher for incident cases and 1.6 times higher for prevalent cases in one practice compared to another practice. Adding practice characteristics to the estimation of incidence and prevalence rates does not result in lower variations between general practices as MORs remain stable for all health problems (Table 2). Considering the variation of osteoarthritis between GPRNs, results show no variation in the incidence rates (MOR 1.02 (95% CI: 1.00-1.45)) and a relatively high variation in prevalence rates (MOR 1.96 (95% CI: 1.48-4.83)). The chance of having a diagnosis of osteoarthritis is about 2 times higher between two randomly chosen GPRNs. We observed hardly any reductions in the variation between GPRNs after the addition of practice characteristics to the analyses (Table 3). The same results are seen for most other diseases.

The influence of EHR software package and province

The influence of EHR software package and province on the variation in incidence and prevalence figures between practices could only be investigated in the LINH network. The effect of EHR software package and province on the variation between practices is small, results are shown in Table 4.

Practices using the software package Medicom© show significantly lower morbidity estimates in 6 out of 10 prevalent disorders. However, this results only in a small decline in variation between practices. For example, in the prevalence of osteoarthritis the MOR between practices decreases from 1.50 (95% CI: 1.38-1.59) to 1.47 (95% CI: 1.37-1.58). For province, practices in 'Groningen' showed higher prevalence figures in 3 out of 10 disorders than the other provinces (results not shown), but statistically the variation between practices did not change. For example, in stroke the variance (in MOR) declined from 1.80 (95% CI: 1.60-1.77) to 1.75 (95% CI: 1.56-1.91).

Table 2 The influence of practice characteristics on the variation of incidence and prevalence figures between general practices

MORBIDITY	MOR (95%CI)						
	Population characteristics (age, gender, SES, ethnicity and degree of urbanisation)						
	-	Type of practice	%female	Working experience	Practice nurse	Distance to hospital[1]	Distance to out-of-hours service location
Incidence							
Urinary tract infection	**1.33** 1.25-1.47	**1.32** 1.24-1.46	**1.31** 1.24-1.40	**1.34** 1.25-1.48	**1.32** 1.24-1.46	**1.34** 1.25-1.48	**1.33** 1.25-1.48
Gastro-intestinal infection	**1.52** 1.39-1.67	**1.50** 1.37-1.66	**1.52** 1.38-1.67	**1.53** 1.39-1.69	**1.53** 1.39-1.69	**1.53** 1.39-1.68	**1.53** 1.39-1.69
Neck and back problems	**1.23** 1.17-1.32	**1.23** 1.17-1.32	**1.22** 1.17-1.32	**1.23** 1.17-1.32	**1.23** 1.18-1.32	**1.22** 1.17-1.31	**1.23** 1.18-1.32
Eczema	**1.29** 1.22-1.40	**1.28** 1.22-1.40	**1.28** 1.22-1.40	**1.27** 1.21-1.38	**1.28** 1.22-1.40	**1.28** 1.22-1.40	**1.29** 1.22-1.40
Asthma	**1.73** 1.53-1.95	**1.75** 1.55-1.99	**1.70** 1.51-1.92	**1.73** 1.53-1.96	**1.73** 1.54-1.96	**1.72** 1.53-1.95	**1.72** 1.52-1.94
COPD	**1.42** 1.28-1.60	**1.41** 1.27-1.61	**1.41** 1.27-1.61	**1.41** 1.27-1.60	**1.39** 1.28-1.57	**1.44** 1.30-1.63	**1.43** 1.28-1.62
Osteo-arthritis	**1.42** 1.30-1.55	**1.43** 1.31-1.57	**1.42** 1.30-1.55	**1.41** 1.29-1.55	**1.43** 1.31-1.57	**1.41** 1.30-1.54	**1.42** 1.30-1.55
Diabetes Mellitus	**1.65** 1.47-1.85	**1.58** 1.42-1.79	**1.61** 1.44-1.82	**1.63** 1.46-1.84	**1.65** 1.47-1.86	**1.65** 1.48-1.86	**1.66** 1.48-1.87
CHD	**1.65** 1.46-1.88	**1.63** 1.45-1.87	**1.63** 1.45-1.86	**1.66** 1.47-1.90	**1.65** 1.47-1.89	**1.65** 1.47-1.89	**1.65** 1.46-1.89
Stroke	**1.36** 1.24-1.53	**1.34** 1.19-1.52	**1.37** 1.23-1.54	**1.37** 1.24-1.54	**1.37** 1.23-1.54	**1.37** 1.24-1.54	**1.36** 1.22-1.54
Depression	**1.46** 1.34-1.62	**1.44** 1.32-1.59	**1.45** 1.33-1.61	**1.47** 1.34-1.64	**1.47** 1.35-1.64	**1.44** 1.32-1.60	**1.46** 1.34-1.63
Anxiety	**1.54** 1.40-1.71	**1.50** 1.37-1.66	**1.46** 1.34-1.61	**1.55** 1.41-1.72	**1.54** 1.40-1.71	**1.55** 1.41-1.72	**1.55** 1.41-1.72

MORBIDITY	MOR (95%CI)						
	Population characteristics (age, gender, SES, ethnicity and degree of urbanisation)						
	-	Type of practice	%female	Working experience	Practice nurse	Distance to hospital[1]	Distance to out-of-hours service location
Prevalence							
Neck and back problems	**1.41** 1.36-1.49	**1.40** 1.36-1.48	**1.41** 1.37-1.49	**1.41** 1.37-1.49	**1.41** 1.36-1.49	**1.41** 1.37-1.49	**1.41** 1.36-1.49
Eczema	**1.60** 1.52-1.72	**1.60** 1.52-1.72	**1.60** 1.53-1.72	**1.60** 1.53-1.73	**1.60** 1.53-1.73	**1.60** 1.53-1.73	**1.58** 1.51-1.70
Asthma	**1.65** 1.57-1.73	**1.66** 1.57-1.74	**1.65** 1.57-1.73	**1.65** 1.57-1.73	**1.64** 1.56-1.72	**1.65** 1.57-1.73	**1.64** 1.56-1.72
COPD	**1.68** 1.59-1.77	**1.69** 1.53-1.78	**1.68** 1.52-1.77	**1.68** 1.52-1.78	**1.66** 1.51-1.75	**1.68** 1.59-1.77	**1.68** 1.59-1.77
Osteo-arthritis	**1.60** 1.46-1.68	**1.59** 1.45-1.67	**1.60** 1.46-1.68	**1.60** 1.46-1.68	**1.59** 1.46-1.67	**1.60** 1.46-1.68	**1.60** 1.46-1.68
Diabetes Mellitus	**1.52** 1.46-1.59	**1.53** 1.46-1.59	**1.53** 1.46-1.59	**1.53** 1.56-1.59	**1.51** 1.45-1.58	**1.52** 1.46-1.59	**1.53** 1.46-1.59
CHD	**1.91** 1.78-2.03	**1.90** 1.78-2.03	**1.89** 1.77-2.02	**1.91** 1.79-2.04	**1.90** 1.77-2.03	**1.92** 1.79-2.04	**1.90** 1.77-2.03
Stroke	**1.76** 1.73-1.88	**1.77** 1.73-1.89	**1.77** 1.73-1.89	**1.77** 1.73-1.89	**1.77** 1.73-1.89	**1.75** 1.71-1.86	**1.77** 1.73-1.89
Depression	**1.71** 1.62-1.80	**1.72** 1.62-1.81	**1.71** 1.62-1.81	**1.71** 1.62-1.81	**1.71** 1.62-1.81	**1.71** 1.62-1.80	**1.71** 1.59-1.77
Anxiety	**1.74** 1.64-1.83	**1.75** 1.64-1.85	**1.73** 1.64-1.85	**1.74** 1.64-1.83	**1.74** 1.65-1.84	**1.74** 1.64-1.83	**1.71** 1.62-1.80

Note: **Bold:** all differences between practices are significant.
Shaded cells represent a significant influence of the specific practice characteristic on morbidity estimation ($p < 0.05$), corresponding odds ratio is not reported. [1] Level of urbanization of the home address of the patient is not considered, because of high correlation to distance to hospital.

DISCUSSION

Our results show that only a small number of practice characteristics was related to morbidity estimates. Adjusting for these practice characteristics hardly reduced the variation of morbidity estimates between networks or practices. We did not find any apparent influence of GP or practice characteristics on the variation in morbidity estimates between GPRNs.

Practice characteristics cannot explain the variation between GPRNs or general practices. Still, we found that in group practices more patients were diagnosed with diabetes and anxiety disorders, and practices with a practice nurse showed more patients with the diagnoses COPD. Similar to our findings, in Nielen et al. group practices were associated with higher estimates of incidence of diabetes mellitus (OR = 1.3).[22] Practice nurses mainly support the GP in monitoring and treating patients with chronic diseases, e.g. diabetes mellitus, CHD, COPD and asthma. A possible explanation for higher prevalence figures of COPD is that a practice nurse with regular contact with these patients keeps better records than the GP.

The relation between psychological problems, such as depression or anxiety, and distance to nearest hospital or out-of-hour service location is probably due to the relationship between large cities and psychological problems. Both psychological problems and smaller distances to a hospital or out-of-hour service locations are more apparent in large cities.[23, 24] Causes and consequences of depression (Dutch This is shown in the high correlation found between the urbanization level of patient's home address and the distance from general practice to the nearest hospital.

To our knowledge, this is the first research that investigates the direct influence of GP and practice characteristics on the variation of morbidity estimates between registration networks, not on the actual morbidity estimation. We explored the practice characteristics that, in earlier research, showed any relevance to morbidity estimation.[8-10] However, we must comment that we found particularly small number of significant relations between morbidity figures and practice

Table 3 The influence of practice characteristics on the variation of incidence and prevalence estimates between general practice registration networks

	MOR (95%CI)						
	Population characteristics (age, gender, SES, ethnicity and degree of urbanisation)						
MORBIDITY	**-**	**Type of practice**	**%female**	**Working experience**	**Practice nurse**	**Distance to hospital[1]**	**Distance to out-of-hours service location**
Incidence							
Urinary tract infection	1.18 1.00-1.66	1.19 1.00-1.69	1.20 1.00-1.71	1.12 1.00-1.55	1.19 1.00-1.68	1.18 1.00-1.66	1.18 1.00-1.68
Gastro-intestinal infection	**1.44** 1.20-2.66	**1.43** 1.18-2.64	**1.41** 1.16-2.53	**1.44** 1.19-2.66	**1.44** 1.19-2.66	**1.45** 1.20-2.67	**1.44** 1.20-2.66
Neck and back problems	**1.29** 1.12-1.98	**1.28** 1.11-1.95	**1.28** 1.11-1.95	**1.29** 1.13-1.98	**1.29** 1.12-1.99	**1.29** 1.13-1.98	**1.29** 1.12-1.98
Eczema	1.18 1.00-1.66	1.17 1.00-1.66	1.18 1.00-1.68	**1.24** 1.05-1.84	1.16 1.00-1.62	1.17 1.00-1.65	1.17 1.00-1.65
Asthma	**1.39** 1.09-2.71	**1.37** 1.06-2.69	**1.47** 1.15-2.97	**1.38** 1.08-2.68	**1.41** 1.10-2.86	**1.39** 1.09-2.72	**1.38** 1.09-2.86
COPD	**1.40** 1.13-2.69	**1.48** 1.16-3.04	**1.45** 1.16-2.82	**1.40** 1.13-2.64	**1.49** 1.19-3.05	**1.42** 1.13-2.82	**1.40** 1.13-2.69
Osteo-arthritis	1.02 1.00-1.42	1.02 1.00-1.44	1.00 1.00-1.52	1.03 1.00-1.44	1.03 1.00-1.44	1.08 1.00-1.48	1.02 1.00-1.42
Diabetes Mellitus	1.00 1.00-1.45	1.14 1.00-1.71	1.15 1.00-1.74	1.00 1.00-1.58	1.00 1.00-1.61	1.00 1.00-1.55	1.00 1.00-1.56
CHD	1.00 1.00-1.42	1.00 1.00-1.71	1.00 1.00-1.60	1.00 1.00-1.60	1.00 1.00-1.58	1.00 1.00-1.56	1.00 1.00-1.56
Stroke	1.20 1.00-1.88	1.27 1.00-2.14	1.19 1.00-1.87	1.17 1.00-1.80	1.21 1.00-1.93	1.21 1.00-1.91	1.21 1.00-1.91
Depression	1.38 1.00-2.79	**1.51** 1.10-3.24	1.41 1.00-2.76	1.38 1.00-2.77	1.38 1.00-2.80	**1.48** 1.06-3.11	1.39 1.00-2.79
Anxiety	**1.66** 1.17-4.07	**1.78** 1.29-4.72	**1.73** 1.29-4.30	**1.66** 1.17-4.09	**1.70** 1.20-4.30	**1.75** 1.23-4.55	**1.65** 1.17-4.06

	MOR (95%CI)						
	Population characteristics (age, gender, SES, ethnicity and degree of urbanisation)						
MORBIDITY	**-**	**Type of practice**	**%female**	**Working experience**	**Practice nurse**	**Distance to hospital[1]**	**Distance to out-of-hours service location**
Prevalence							
Neck and back problems	**1.90** 1.46-4.38	**1.92** 1.47-4.47	**1.91** 1.47-4.42	**1.90** 1.46-4.37	**1.90** 1.47-4.40	**1.90** 1.47-4.40	**1.89** 1.46-4.33
Eczema	**1.57** 1.29-2.91	**1.59** 1.30-2.99	**1.55** 1.27-2.83	**1.57** 1.29-2.92	**1.57** 1.29-2.93	**1.56** 1.28-2.86	**1.57** 1.29-2.94
Asthma	**1.37** 1.11-2.20	**1.37** 1.11-2.21	**1.36** 1.10-2.20	**1.37** 1.11-2.21	**1.37** 1.11-2.21	**1.38** 1.11-2.24	**1.38** 1.12-2.24
COPD	**1.46** 1.18-2.55	**1.44** 1.16-2.52	**1.44** 1.14-2.49	**1.46** 1.17-2.55	**1.42** 1.15-2.42	**1.46** 1.18-2.57	**1.46** 1.18-2.59
Osteo-arthritis	**1.96** 1.48-4.83	**2.00** 1.50-5.04	**1.97** 1.48-4.87	**1.98** 1.48-4.92	**1.99** 1.49-5.00	**1.99** 1.49-4.99	**1.96** 1.48-4.85
Diabetes Mellitus	**1.34** 1.11-2.08	**1.35** 1.12-2.12	**1.34** 1.11-2.09	**1.34** 1.11-2.09	**1.33** 1.11-2.05	**1.34** 1.11-2.08	**1.34** 1.11-2.08
CHD	**2.38** 1.65-7.69	**2.40** 1.65-7.77	**2.34** 1.63-7.42	**2.39** 1.65-7.74	**2.38** 1.64-.63	**2.37** 1.64-7.60	**2.43** 1.67-8.03
Stroke	**2.20** 1.57-6.36	**2.21** 1.58-6.47	**2.19** 1.57-6.33	**2.20** 1.57-6.37	**2.19** 1.57-6.33	**2.18** 1.56-6.25	**2.23** 1.58-6.57
Depression	**1.58** 1.27-3.06	**1.59** 1.27-3.10	**1.56** 1.24-2.98	**1.59** 1.27-3.08	**1.59** 1.27-3.09	**1.58** 1.26-3.07	**1.58** 1.27-3.03
Anxiety	**1.50** 1.19-2.75	**1.51** 1.20-2.80	**1.47** 1.15-2.63	**1.52** 1.20-2.82	**1.50** 1.19-2.76	**1.50** 1.19-2.78	**1.51** 1.20-2.77

Note: **Bold:** Significant variation between GPRNs.
Shaded cells represent a significant influence of the specific practice characteristic on morbidity estimation ($p < 0.05$), corresponding odds ratio is not reported. 1 Level of urbanization of the home address of the patient is not considered, because of high correlation to distance to hospital.

characteristics. Unfortunately, we could only investigate GP characteristics aggregated on the practice level. This may have diminished the effect of these characteristics on morbidity estimation. Though, research showed that GPs in one practice are more similar than GPs between practices, because a GP's medical practice is affected by the working environment.[8, 10, 25, 26] Furthermore, Marinus[8] concluded that the investigation of individual GP characteristics on variation would be less effective. Therefore studying the variation at the practice level is legitimate.

A drawback of this study is that we could not differentiate between actual morbidity differences and artefacts of the recording system. Differences between provinces may reflect real differences in health status between populations[27], although there is no reason to expect such large differences of these twelve diseases within a small country as the Netherlands. Overall, no clear effect of province is seen in our data.

Another possible artefact is the type of EHR to record morbidity. Practices using the Medicom© software package showed lower prevalence figures of osteoarthritis, asthma, eczema, depression, anxiety disorders and neck and back problems. Medicom© automatically ends an episode if there

Table 4 The influence of "EHR software package" and "province" on the variation between morbidity estimates of LINH general practices#

	MOR (95%CI)				
	Population characteristics (age, gender, SES, ethnicity and degree of urbanization				
Health problem	**-**	**EHR software package**		**Province**	
Incidence					
Urinary tract infection	-		-		-
Gastro-intestinal infection	-		-		-
Neck and back problems	1.24 1.17-1.35		-		-
Eczema	1.27 1.20-1.40		-		-
Asthma	1.74 1.52-2.11		-		-
COPD	-		-		-
Osteoarthritis	-		-		-
Diabetes Mellitus	1.88 1.60-2.37		-		-
CHD	2.03 1.68-2.65		-	1.86 1.57-2.40	Zeeland[1]
Stroke	1.49 1.30-1.82		-		-
Depression	1.47 1.33-1.69		-		-
Anxiety	1.60 1.43-1.87	1.51 1.36-1.76	Promedico[1]		-
Prevalence					
Neck and back problems	1.33 1.28-1.40	1.29 1.25-1.36	Medicom[1]		-
Eczema	1.52 1.44-1.66	1.50 1.42-1.63	Microhis[1]		-
		1.46 1.39-1.58	Medicom[1]		
		1.50 1.42-1.66	Mira[1]		
Asthma	1.59 1.50-1.75	1.57 1.48-1.71	Microhis[1]		-
		1.56 1.47-1.71	Medicom[1]		
COPD	1.64 1.49-1.75		-		-
Osteoarthritis	1.50 1.38-1.59	1.47 1.36-1.56	Medicom[1]		-
Diabetes Mellitus	1.38 1.30-1.48		-	1.36 1.28-1.45	Gelderland[1]
CHD	2.03 1.77-2.23		-		-
Stroke	1.80 1.60-1.97		-	1.75 1.56-1.91	Groningen[1]
Depression	1.61 1.51-1.77	1.58 1.48-1.73	Medicom[1]	1.56 1.43-1.72	Groningen[1]
Anxiety	1.71 1.59-1.90	1.62 1.52-1.78	Microhis[1]	1.67 1.56-1.85	Groningen[1]
		1.65 1.54-1.82	Medicom[1]		

[#] This table only present the practice characteristics that significantly influenced morbidity estimation on [1] 0.05 level.
Note: All variations (in MOR) between general practices are significant in all diseases.

is no regular contact for this specific health problem. This is often the case in osteoarthritis or stroke. Two GPRNs (SMILE and RNUH Leo) contain only practices, which use the Medicom© software package, but these GPRNs do not show lower prevalence estimates of osteoarthritis (as we would expect regarding their software package). If a GP marked an episode of osteoarthritis as an episode with special attention, the episode would have stayed active, suggesting a different recording strategy between the different GPRNs.

Other research also showed that inter-doctor variation in morbidity estimates remains high after adjusting for population and practice characteristics.[25] Westert and de Bakker[25] suggested that better use of classification systems by training of GPs might be effective in narrowing the variation. Similar results about the lower number of episodes in practices using Medicom© compared to other EHR software packages were found by Khan et al.[28] In their follow up study they observed an increase of the recording quality of the electronic patient records and less variation between practices and between EHR software packages.[29]

Variation in morbidity estimates can occur on different stages of the recording process, at the consultation, recording in the EHR, data extraction, data storage, analyses and use of the data for estimation of incidence and prevalence figures. In a previous paper, we investigated the influence of population characteristics on morbidity estimates; in this current research we added the influence of practice characteristics.[6] However, neither population nor practice characteristics could explain the variation between incidence and prevalence estimates between practices or GPRNs. A next step is to investigate the effects of recording agreements of different GPRNs on morbidity variations between GPRNs. The variation between GPRNs is much higher in prevalence figures compared to incidence figures, which might be related to different methods of calculating morbidity.[5, 26] For example, some networks only count disease episodes when a patient had contact for that disease in a particular year, as others also include single contacts (not linked to an episode) or episodes with problem status. Understanding the differences between GPRNs and practices is needed to come to the most valid and reliable estimate for morbidity rates in the general population using general practice based data.

CONCLUSIONS

The goal of this study was to explain differences in morbidity estimates from different GPRNs. We investigated to what extent differences in characteristics of general practices could explain this variation. Our results show that only a small number of practice characteristics was related to morbidity estimates. Adjusting for these practice characteristics hardly reduced the variation between networks or practices. Therefore, we conclude that GPs and practice characteristics do not explain the differences in incidence and prevalence figures between different networks.

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Participating general practice registration networks

ANH-VUmc, Academic General Practice Network of VU University medical centre.
CMR-N, Continuous Morbidity Registration Nijmegen.
LINH, Netherlands Information network of General Practice, changed in 2013 to “NIVEL Primary Care Database” (NIVEL-PCD).
RNUH-LEO, Registration network of General Practitioners associated with Leiden University.
SMILE, Study of Medical Information and Lifestyle in Eindhoven.
Trans, Transition Project.

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CHAPTER 5

Quality aspects of Dutch general practice based data: a conceptual approach

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ABSTRACT

Background: General practice-based data, collected within general practice registration networks (GPRNs), are widely used in research. The quality of the data is important, but the recording criteria about what type of information is collected and how this information should be recorded differ between GPRNs.

Objective: We aim to identify aspects that describe the quality of general practice-based data in The Netherlands.

Methods: To investigate the quality aspects, we used the method of concept mapping, a structured conceptualization process for a complex multi-dimensional topic. We explored the ideas of representatives from ten Dutch GPRNs on the quality of general practice based data in five steps: preparation, generation of statements, structuring, representation and interpretation. In a brainstorm session ten experts generated statements about good data quality from general practice, which we completed with information from the literature. In total eighteen experts participated in the ranking and clustering of the statements. These results were analyzed in ARIADNE software, using a combination of principal component analysis and cluster analysis techniques. Finally, the clusters were labelled based on their content.

Results: A total of 72 statements were analyzed, which resulted in a two-dimensional picture with six clusters, “complete health record”, “coding of information”, “episode oriented recording”, “diagnostic validity”, “recording agreements” and “residual category”

Conclusion: The quality of general practice based data can be considered on five content based aspects. These aspects determine the quality of recording.

Keywords: classification, episodes of care, data quality, general practice, medical records, registries.

INTRODUCTION

General practitioners’ (GPs) first priority is to provide high quality patient care. GPs record information in an electronic health records (EHR) to account for the given patient care. Structuring of this information gives an overview of the patients’ health problems.[1] For daily patient care up to date, complete and valid information is necessary. General practice registration networks (GPRNs) collect information from individual practices and collate the data in a (central) database, for other purposes than daily patient care. This routinely recorded data is widely used in research, e.g. to evaluate health care, to estimate morbidity rates or to observe health inequalities.[2-6]

GPs and practices, participating in such a GPRN, agreed to record information according to the recording quality standards of the specific network, to create uniform data. All networks collectively support the need for qualitatively good data, as a lot of effort is put into assuring data quality (training of GPs, cleaning of data, data feedback to the practice, meetings of GPs about diagnostic classification and recording). However, the recording criteria about what type of information is gathered (all morbidity or only more severe cases), how this information is recorded and why this information is collected (educational purpose, morbidity estimation, provision of a sampling frame) differ between GPRNs.[7-9] These different operational criteria about data recording and collection of the GPRNs might reflect different conceptual perspectives of good data quality.

In the literature, much attention is paid to the completeness and correctness of data.[10-16] We do acknowledge the importance of these aspects, and we investigate whether other aspects, e.g. structuring of the data, are also important to describe the quality of the data.[17, 18] Currently, there is no consensus of how practice based data quality should be described and how it is usable for research.[19] Other valuations of data quality aspects can result in different interpretations of the data derived from different GPRNs. Therefore, our goal is to give a complete picture of the concept of data quality from general practice from the GPRN perspective.

In this study, we explored the conceptual ideas of representatives from Dutch GPRNs on the quality of general practice-based data. We aim to identify common aspects, resulting in a conceptual framework to describe quality of Dutch general practice based data.

METHODS

Concept mapping

We used the method of concept mapping to investigate common aspects of good quality of general practice-based data. Concept mapping is a structured conceptualization process to explore the conceptual ideas of experts about a complex multi-dimensional topic.[20] The outcome of this process is a concept map; a visual representation of the group’s thinking which summarizes all ideas of the group. Concept mapping consists of six sequential steps: preparation, generation of statements, structuring, representation, interpretation and utilization. In this article, we report on steps one to five. In the discussion, we reflect on utilization of the concept map.

Preparation

We defined the central question "What determines good quality of data from general practice?" as the starting point of the exercise. This research is part of a larger study that tries to explain differences in morbidity estimation between Dutch GPRNs. In this study ten GPRNs are represented, fifteen experts of these ten Dutch GPRNs were invited to participate in a brainstorm session to generate the statements about this topic to ensure a broad spectrum of ideas. These experts have been intensively working with general practice-based data in different positions: data manager, scientific researcher or general practitioner. In the structuring step we invited nineteen experts of the ten participating GPRNs to obtain a broader and more solid map, because the data analysis (principal component analysis and cluster analysis) runs better with more information.

Generation of statements

We planned a two-hour meeting with the experts for a brainstorm session to generate statements about good quality of general practice-based data. First, we explained the process of concept mapping. Next, participants were asked to answer the central question by generating as many statements as possible.

The brainstorm session was divided into two parts. In the first part the participants wrote down as many short phrases or sentences as they could think of, which described characteristics of qualitatively good general practice based data. Writing down the statements was to ensure input from every participant. In the second part, we gathered the written statements and, in rotation, we invited every participant to explain the statements and duplicate statements were removed. Discussion about the legitimacy of the statements was not allowed during the meeting. Checking the statements was important to explain their meaning. Sometimes rephrasing was necessary to make the statements clear and to ensure that a statement contained only one aspect of quality. We encouraged the participants to keep writing new ideas during the second part of the session. After the brainstorm session the authors added several aspects from the literature, which they believed to be relevant, but were not mentioned by the participants during the brainstorm.

Structuring

In the structuring stage, we asked the experts, who participated in the brainstorm session, to invite other experts from their GPRN to broaden the basis of the exercise. At this stage, statements were structured to generate their interrelationship. Every statement was printed on a separate index card and sent to every participant. Structuring was carried out in two ways.

Ranking: The participants rated all statements on a 5-point Likert scale, where '1' is not important and '5' very important as a criterion for data quality.

Clustering: The participants grouped the statements into a limited number of clusters based on meaning or similarity. This should be an associative process, without exhaustive reasoning of all possible associations. After clustering, the participants gave every cluster a label which covered the connection between the statements.

Representation

The findings of the participants were analysed using ARIADNE software, especially designed for concept mapping.[21] The data was analysed using a combination of principal component analysis and cluster analysis techniques. ARIADNE first computed a binary symmetric similarity matrix for each participant; two statements in the same cluster were set at 1. Second, all individual matrices were aggregated into one group matrix. Statements that were often linked together had high numbers, meaning that they are conceptually more similar and correlate in some way. This group matrix was used as input for non-metric principal component analysis (PCA), a technique for translating the correlation between statements into coordinates in a multi-dimensional space. The first two dimensions of the PCA solution for each statement were plotted in a point map.

Furthermore, cluster analysis was used to group individual statements on the point map into clusters. Each cluster reflected a conceptual domain or aspect. The authors evaluated all possible clusters, using a cluster tree. We started with a cluster solution of 20 clusters. Each time the analysis moved to a lower number of clusters (e.g. from 20 to 19 clusters) we examined if clustering of the statements was more meaningful for conceptualization. Two criteria for a more meaningful conceptualization were: (1) statements clustered together represent the same conceptual idea, and (2) two individual clusters do not represent the same conceptual idea.

Interpretation

After analysing the different outcomes, the experts determined during a second face-to-face meeting the final number of clusters and discussed the labelling of the clusters. The input for this discussion was sent to the experts before the meeting. Finally, based on the discussion with the experts, the authors determined the definitive labels and identified the two dimensions (the axes of the concept map).

RESULTS

Experts

Representatives of the ten participating GPRNs were invited to participate in this study. Ten experts of nine GPRNs took part in the brainstorm session. To obtain more power to the conceptual picture, nineteen experts were invited to rank and cluster the statements. In total 18 experts returned their findings of which 17 could be analyzed in ARIADNE. If there were any missing data, we asked the participants to complete the information. One expert, who did not participate in the generation of the statements, clustered more than forty statements in one cluster and was therefore excluded from the analyses. Ten experts of nine of the participating GPRNs attended (eight experts of eight GPRNs also participated in the brainstorm session) the second meeting about the interpretation of the results.

Statements

During the brainstorm session, the participants generated 65 statements about data quality from general practice. After the session, the first author added seven statements from the literature,

which resulted in a total of 72 statements (see Table 1 in the supplement).[22, 23] Most statements are related to the content and methods of the information that should be recorded in the general practice registrations.

The statements rated as most important were statements about structuring of information, “no bulk episodes, individual complaints or disorders are recorded under different episodes of care” (mean rating 4.61) and coding of information “all episodes of care are (ICPC) coded” (mean rating 4.56). These aspects are important to identify health problems in the database. Statements, rated as least important, were “one episode of care includes sufficient sub-encounter codes that deviate from the episode title” (mean rating 1.61) and “codes entered in the GP information system are checked by another person” (mean rating 1.67). Table 1 shows the top 5 of highest and lowest rated statements.

Table 1 Top 5 highest and lowest rating of statements

	HIGHEST rating	Rating
1	No bulk episodes, individual complaints or disorders are recorded under different episodes of care	4.61
2	All episodes of care are (ICPC-)coded	4.56
3	Within a GPRN, there are clear, unambiguous registration agreements, that are not multi-interpretable	4.28
4	Information from out-of-hour practice is recorded in the patient’s medical record	4.28
5	Each sub-encounter is ICPC-coded or recorded under the correct episode of care	4.22
	LOWEST rating	**Rating**
1	One episode of care includes sufficient sub-encounter codes that deviate from the episode title	1.61
2	Codes entered in the GP information system are checked by another person	1.67
3	The end date of the medication is actively entered in the GP information system, if not by default	1.94
4	All background information of the patient is kept up to date (may require active inquiry)	1.94
5	A patient record is actively included in the database by the GP when the record is complete	2.00

Cluster map

Five possible cluster maps were considered in the second meeting (number of 4 to 8 clusters). All experts agreed that the concept map with six clusters was the best solution, see figure 1.

Next, we labelled the clusters based on content, representing the different aspects of quality of general practice based data. The cluster “complete health record” refers to all information available about patient’s health, including information from out-of-hour practice, a patient’s history, lab results etc. “Coding of information” means that the diagnoses in the EHR need to be coded with a classification (mostly with International Classification of Primary Care) and not only recorded as free text. This is important as GPRN often do not have access to free text information. “Episode oriented recording” is a method of structuring health care information in episodes of care. Episodes of care contain information (about diagnosis, referrals, interventions, and medication) regarding one specific health problem, starting at the first contact for that problem and ending with the last

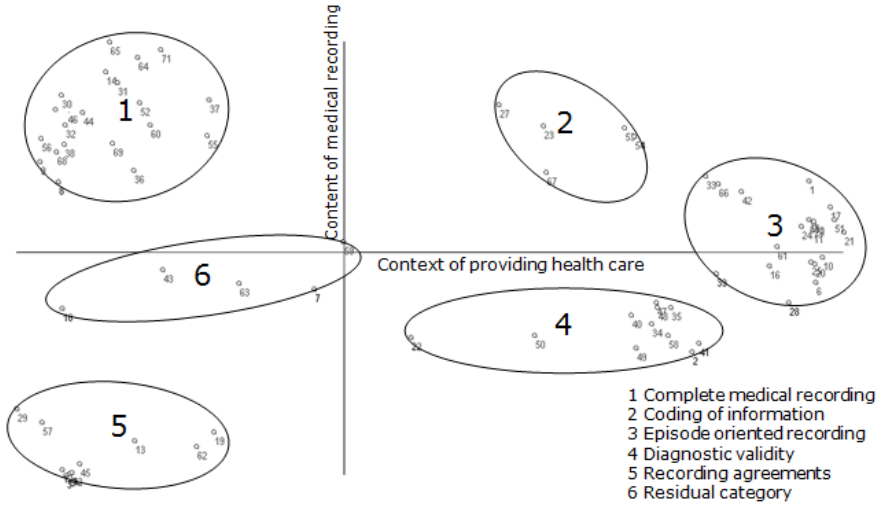

Figure 1 Concept map – Quality aspects of general practice based data

contact for that problem.[24] The “diagnostic validity” refers to correct information and classification of a patient’s health problem. Do all recorded codes in the database represent the health status of that particular patient? “Recording agreements” determine what information is available and how this should be recorded. For example, some GPRNs agreed to only record problems that are severe. The “residual category” is a group of statements without a content based connection. Table 2 shows the six clusters with a selection of corresponding statements. Determination of the cluster ratings was based on the mean rating of all statements included in a cluster, the cluster “episode oriented recording” (mean 3.36) was rated most important.

We identified the two dimensions of the concept map. The horizontal axis represents the “context of providing health care”. We distinguished at the left end “multi-disciplinary care” (information from health care professionals, e.g. medical specialist, pharmacist, practice assistant) and at the right end “individual GP care” (information from direct patient care between patient and GP). The vertical axis covers the “content of medical recording”, where the lower end represents “basic recording” (conditions or minimal requirements of recording) and the upper end “complete recording” (structural recording of all information available in relation to the patient’s health problems).

DISCUSSION

Summary of main findings

The conceptual framework to describe quality of general practice-based data consists of five content-based clusters; “complete health record”, “coding of information”, “episode oriented recording”, “diagnostic validity” and “recording agreements”. The statements in this conceptual framework

Table 2 Quality aspects of data from general practice based on concept mapping

Quality aspects[1]		Cluster rating[2]	Statements[3]
1	Complete medical record	3.16	Information from out-of-hour practice is recorded in the patient's record
			Important information from patient's medical history, recorded by the previous GP, is transferred to the patient's new medical record[4]
			Medical records of deregistered patients contain data of and reason for deregistration
			Information on multidisciplinary care from the integrated information system is also available in the GP information system
			Data from medical specialists is entered into the patient's medical record
			All contra-indications known to the GP are recorded in patient's medical record
			Encounter information is complete; all past encounters are recorded and visible in the patient's medical record, including the encounters funded under a bundled payment scheme
			All lab results and measurements (including weight and height) are recorded in diagnostic section of the patient's medical record
			All medication is structurally recorded in the patient's medical record (including prescriptions from home visits, out-of-hour practice or specialists)
			All referrals to primary and secondary care can be traced in the referral register of correspondence module of the GP information system
			Correct recording of medical status (temporary stop, ended, continuous)
			All laboratory values are recorded in precise measurements (preferably numeric)
			Causes of death are recorded
2	Coding of information	3.35	All assessment-parts of SOAP include an (ICPC-)coded diagnosis
			Medication is linked to the right episode of care
			All prescriptions are linked to a ICPC code
			All referrals are allocated a (diagnostic) ICPC code
3	Episode oriented recording	3.36	No bulk episodes; individual complaints or disorders are recorded under different episodes of care
			All episodes of care are (ICPC-)coded
			Each sub-encounter is ICPC-coded or recorded under the correct episode[4]
			The problem list is accurate; all relevant health problems are recorded as an 'episode of interest' or are included in the problem list
			Complications of diseases are to be recorded as new episodes of care
			The ICPC codes of all episodes of care are kept up-to-date; changes are recorded
			Co-morbidity is recorded in separate episodes of care
			Diagnoses not only as labelled disease but also as ICPC-coded episode of care
			Episodes that can occur only once are registered only once
			The episode list is updated at every patient encounter
			All problems or 'episodes of interest' are actively kept up-to-date regarding active and inactive status
			Each sub-encounter can be recorded under only one episode of care
			All referrals are linked to an episode of care

Quality aspects[1]		Cluster rating[2]	Statements[3]
4	Diagnostic validity	2.97	All patients with an active diagnostic ICPC code actually have that disease/disorder[4]
			Coding 'at the true level of understanding'
			Coding 'at the highest level of understanding'
			ICPC codes match the patients' conditions
			Only valid use of classification categories 'others'; no escape codes are used
			A sufficient number of ICPC codes is recorded; ICPC codes cover the entire encounter
5	Recording agreements	3.01	Within a GPRN, there are clear unambiguous registration agreements, that are not multi-interpretable
			Registration rules and agreements are well communicated and familiar to all practice team members
			GPs consult periodically about the quality of recording
			There are no big differences in recording quality between practice team members
			There are clear registration agreements between practice team members
			Regularly providing actual data (by appointment)
6	Residual category	2.46	Complete recording for care purposes not just for reimbursement or billing

[1] Aspects of data quality (cluster sorted from most to least importance). [2] Mean cluster ranking based on all included statements. [3] Statements ranked ≥3.00 to represent a specific cluster. [4] Statements included from literature.

contain mainly characteristics about what information should be recorded and how this should be structured, which is also recognized in the sequence of importance of the different clusters "episode oriented recording", "coding of information" and "complete health record".

Strengths and limitations of the study

Ten of the eleven major GPRNs in the Netherlands were represented in this research and the experts had different backgrounds. One GPRN expert was not able to participate in the brainstorm session, but participated in ranking and clustering the statements and the discussion meeting. One GPRN was not interested in participating in the study. This GPRN differs from other networks as it uses free text instead of only coded information. If this network would be represented in this study, this might have led to a lower importance value of the cluster "coding of information".

Ten experts of nine Dutch GPRNs participated in the brainstorm session to generate statements that determine good quality of data. Although this group brought up a broad range of statements, the concept map only represents the ideas of this group of experts. Therefore we need to be careful in generalizing the results. To diminish the chance of missing important statements about GP data, we added statements (rates ranging from 1.94 to 4.28) found in the literature. The experts did not question the relevance, validity or meaning of these statements.

As this study was limited to Dutch GPRNs, international generalization of the outcomes can be difficult. For example, "episode oriented recording" is a method which is currently common in the Netherlands. Using this method, GPs organize the information of separate consultations for the

same disease in a episode of care, which makes it possible to investigate transition over time (e.g. cough evolves to be a pneumonia). In other countries and other information systems, where the data is structured differently, some quality aspects may be of less relevance.

Comparison with existing literature

The literature on data quality in general practice emphasizes the importance of completeness and correctness.[10-13, 15, 16] In this study the cluster "diagnostic validity" represents correctness, apparent in the statements "All patients with an active diagnostic International Classification of Primary Care (ICPC) code actually have that disease/disorder" and "ICPC codes match the patients' conditions". However, this cluster was not ranked as most important (mean value of 2.97 on a scale from 1 to 5). A reason for this might be that the experts respect the GPs to be medical experts and that diagnostic validity is already important for daily patient care.

Completeness of the data is represented in "complete health record", implying that all information from different health care professionals and lab results should be recorded. Research about quality showed that prescriptions are best recorded.[12] Structuring of data into episodes of care is ranked most important. This way of structuring, e.g. linking different information (prescriptions, referrals etc.) to one health problem, makes it more plausible that a person actually has the specific disease and therefore this represents a better quality of the diagnostic information. Structuring of data in episodes of care is also important to distinguish new from existing health problems and to investigate whether a problem is recurring.[24]

Training of GPs in using a classification system (e.g. ICPC) is essential for the quality of coding.[6] All GPRNs train their participating GPs in recording coded information. They also give feedback about their recording performance on a regular basis.[7] This may be the reason that "coding of information" is rated as second important aspect. The cluster "residual category" is rated least important; in the second meeting no expert recognized a label covering the content of this cluster. There was also lot of discussion on the validity of the statements in this cluster. The statement "A patient record is actively included in the database by the GP when the record is complete", for example, only concerns one specific GPRN and is therefore not important to the overall data quality from general practice.

Implications for future research or clinical practice

This concept map can be used to determine data quality of general practice registrations. The next step is to make the statements operational and measurable. To distinguish sufficient quality from poor quality, criteria about the level of variation should be formulated.

The purpose of using routine-based data from general practice will result in different interpretations of the concept map, because for different purposes different aspects of quality are important. For example, valid diagnoses and correct identification of new and existing episodes are of vital importance for the determination of morbidity in the population. When investigating the quality of health care, additional quality aspects are required, including "coding of information", "episode

oriented recording", and "complete health record". Furthermore, the availability of information that is not in the register plays a role. GPs have also access to "not recorded" (from memory) and "not coded" (free text) information, information that researchers using the data lack. This makes structural recording and coding of information especially important for data used for secondary purposes.

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SUPPLEMENT 1

Table 1 72 statements of quality of general practice based data

NR	Statement ENG	Mean rating	Cluster
1	No bulk episodes; individual complaints or disorders are recorded under different episodes of care	4.61	3
25	All episodes of care are (ICPC-)coded	4.56	3
5	Within a GPRN, there are clear, unambiguous registration agreements, that are not multi-interpretable	4.28	5
46	Information from out-of-hour practice is recorded in the patient's medical record	4.28	1
33	*Each sub-encounter is ICPC-coded or recorded under the correct episode of care*[1]	4.22	3
34	*All patients with an active diagnostic ICPC code actually have that disease/disorder*[2]	4.17	4
23	All assessment-parts of SOAP (subjective, observation, assessment, plan) include an (ICPC-) coded diagnosis	4.06	2
47	Coding 'at the true level of understanding' (component 1 if component 7 is uncertain/ complaint versus diagnosis)	4.06	4
36	*Important information from the patient's medical history, recorded by the previous GP, is transferred to the patient's new medical record*[1, 3]	4.00	1
24	The problem list is accurate; all relevant health problems are recorded as an 'episode of interest' or are included in the problem list	3.94	3
26	All sub-encounters are linked to an episode of care	3.94	3
72	Registration rules and agreements are well communicated and familiar to all practice team members	3.94	5
17	Complications of diseases are to be recorded as new episodes of care; for example, retinopathy in patients with diabetes mellitus is to be recorded as a new episode of care distinct from the diabetes mellitus episode of care	3.89	3
48	Coding 'at the highest level of understanding' (if a diagnosis can be made, no complaint codes are used)	3.83	4
21	The ICPC codes of all episodes of care are kept up to date; changes are recorded	3.78	3
42	Co-morbidity is recorded in separate episodes of care	3.78	3
56	Medical records of deregistered patients contain date of and reason for deregistration	3.78	1
68	Information on multidisciplinary care from the KIS (Integrated information system) is also available in the HIS (GP information system)	3.78	1
44	Data from medical specialists is entered into the patient's medical record	3.67	1
61	Diagnoses not only as labeled disease but also as ICPC-coded episode of care	3.61	3
65	All contra-indications (allergies, intolerances, etc.) known to the GP are recorded in the patient's medical record	3.61	1
69	Encounter information is complete; all past encounters are recorded and visible in the patient's medical record, including the encounters funded under a bundled payment scheme	3.61	1
71	All lab results and measurements (including weight and height) are recorded in the diagnostic section of the patient's medical record	3.61	1
52	All medication is structurally recorded in the patient's medical record (including prescriptions from home visits, out-of-hour practices or specialists)	3.56	1
6	Episodes that can occur only once are registered only once	3.50	3
53	Medication is linked to the right episode of care	3.44	2
4	GPs consult periodically about the quality of recording	3.39	5
7	Complete recording for care purposes not just for reimbursement or billing	3.39	6
27	All prescriptions are linked to an ICPC code	3.39	2
3	There are no big differences in recording quality between practice team members	3.33	5
14	All referrals to primary and secondary care can be traced in the referral register or correspondence module of the GP information system	3.28	1
16	The episode list is updated at every patient encounter	3.22	3
31	Correct recording of medication status (temporary stop, ended, continuous)	3.22	1
49	ICPC codes match the patients' conditions (correct distribution between complaint codes and disorder/diagnostic codes)	3.22	4
12	There are clear registration agreements between practice team members	3.17	5
15	All problems or 'episodes with interest' are actively kept up-to -ate regarding active or inactive status	3.17	3
45	Regularly providing actual datasets (by appointment)	3.17	5
55	All laboratory values are recorded in precise measurements (preferably numeric)	3.17	1
58	Only valid use of classification categories 'others'; no escape codes are used	3.17	4
67	All referrals are allocated a (diagnostic) ICPC code	3.17	2
11	Each sub-encounter can be recorded under only one episode of care (if several complaints are presented during one encounter, the complaints can be recorded under different care episodes)	3.06	3
50	A sufficient number of ICPC codes is recorded correctly; ICPC codes cover the entire encounter	3.00	4
64	Causes of death are recorded	3.00	1
66	All referrals are linked to an episode of care	3.00	3
40	*The patient's age and gender match the recorded ICPC codes*[4]	2.94	4
51	Recurring diseases are recorded in a new episode of care	2.94	3
9	All newly registered patients are allocated a registration date	2.89	1
10	Episodes are terminated if no longer relevant	2.83	3
54	Laboratory diagnostics are linked to the right episode of care	2.72	2
57	Reflective information is actually processed	2.72	5
19	A sufficient percentage of all patients is included in the database	2.61	5
32	*All observations of the GP are recorded*[1, 5, 6]	2.61	1
37	Transient contra-indications, like pregnancy, are given an end date, if not automatically terminated by the GP information system	2.61	1
29	Data entered by different team members can be traced back to individual team members	2.56	5
43	No double entries (e.g. two leaving dates)	2.56	6
8	All newly registered patient are allocated a patient category	2.50	1
28	The titles of a sufficient number of episodes of care are changed (progressive insight of GP)	2.50	3
2	Correct distribution between encounters leading to new episodes of care and encounters added to existing episodes of care	2.44	4
70	A comment formulated by the GP is added to the title of the episode of care	2.39	3
13	All registering team members actually have a sufficient number of coded encounters	2.33	5

59	The SOAP (subjective, observation, assessment, plan) is completed for a sufficient percentage of encounters	2.33	6
22	A sufficient number of encounters has multiple ICPC codes/ sub-encounters	2.22	4
30	All background information of the patients is recorded	2.22	1
39	*Episodes of care that require monitoring or continuous medical care have sufficient sub-encounters*[1]	2.22	3
35	Patients have on average sufficient active episodes of care	2.11	4
20	Problems or 'episodes of interest' do not change in name	2.06	3
63	The recorded encounters, codes, medication, etc. are equally distributed in time (no recording gaps in a registration year)	2.06	6
18	A patient record is actively included in the database by the GP when the record is complete	2.00	6
38	*All background information of the patient is kept up to date (may required active inquiry)*[1, 5]	1.94	1
60	The end date of the medication is actively entered in the GP information system, if not by default	1.94	1
62	Codes entered in the GP information system are checked by another person	1.67	5
41	One episode of care includes sufficient sub-encounter codes that deviate from the episode title	1.61	4

Note: Italic statements were derived from literature, see references

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CHAPTER 6

Do quality rules of general practice registration networks fit the theoretical domains of recording quality?

Using neck and back problems and osteoarthritis as examples

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Submitted for publication

ABSTRACT

Background: General practice–based data, collected by general practice registration networks (GPRNs), are widely used in research. The morbidity estimates derived from Dutch GPRNs show unexplained variation. Differences in quality rules may explain some of the variation. In earlier research, we developed a concept map to describe the quality of routinely collected general practice-based data.

Objective: The aim of this study is to describe the quality rules practiced by eight Dutch GPRNs and to explore how these rules fit the quality domains as established in the concept map.

Methods: We identified the applied quality rules concerning neck and back problems and osteoarthritis, categorized these quality rules in the different quality domains, and evaluated the distribution of these quality rules over the quality domains in relation to their rated importance.

Results: In total, 68 unique quality rules were identified. Seven originate from the guideline "adequate recording of the electronic patient record (ADEPD)" from the Dutch College of General Practitioners. In general, more important quality domains include a higher number of quality rules. The number of quality rules is too small to interpret the coverage of the quality domains per GPRN.

Conclusion: A fair distribution of quality rules indicates an acceptable internal validity of the established concept map. The individual GPRNs include only a small number of quality rules, therefore more research is needed to study effect of quality rules on morbidity estimation and the compliance of GPs with the agreed quality rules.

Keywords: Episodes of care, Data quality, General practice, Medical records, Concept mapping, Registries

BACKGROUND

Public health decisions should be based on the best available evidence. Therefore, health policy makers need objective information about the health status of the population. Estimates of disease incidence and prevalence, life expectancy, and mortality are core indicators of population health and health care needs. Information about which diseases occur most frequently and which health problems deserve priority provide guidance to public health policy.[1, 2]

General practice based registration networks (GPRNs) provide information about the patients' health in terms of incidence and prevalence of diseases as known to general practitioners (GPs). The entire non-institutionalized Dutch population has to be registered with a GP and therefore GPRNs include information about the total population in their coverage-area. However, the medically interpreted information about health problems is only available when patients seek medical care. GPRN information is a valuable addition to information from other sources, such as disease specific registers, health examination surveys or health interview surveys. For many diseases, GPRN data is the only medically interpreted registry available.

The information from electronic health records (EHR) of patients kept by individual GPs or practices is collected by GPRNs, which collate the data into a central database. Despite the strengths of Dutch general practice, e.g. gatekeeper role and obligatory listing of patients to a GP, the incidence and prevalence estimates vary substantially between the different GPRNs.[3, 4] A clear understanding of this variation is needed to interpret the validity of the morbidity estimates.

Factors, that may explain the variation between GPRNs are; characteristics of the population listed in the participating practices, characteristics of the participating general practices, methodological aspects (such as recording agreements, the processing of the data or quality assurance), and geographical coverage.[5] Earlier research showed that differences in patient population characteristics, practice characteristics and geographical location explained little, if any, of the variation in morbidity estimations between Dutch GPRNs.[6, 7] Methodological differences might be part of the explanation of the differences in prevalence and incidence rates between the GPRNs. Therefore, these aspects need more consideration. Examples of methodological issues are differences in primary goal, operational definitions, recording agreements, and quality rules of GPRNs.[5]

In this study, we focus on the agreements made by GPRNs with their participating GPs. We refer to these agreements as 'quality rules', because they determine quality of the information available from a specific network. Before we can evaluate the effects of the quality rules on the incidence and prevalence of diseases, we first need to investigate which aspects of data quality are covered by the different quality rules.

In earlier research, we developed a concept map to describe the quality of routinely collected general practice based data. This concept map consists of five domains; 'complete health record', 'classification of information', 'episode oriented recording', 'diagnostic validity', and 'recording agreements.[8] This concept map was developed with the input of experts of ten GPRNs in the Netherlands. A next step is to empirically test this concept map in practice.

The aim of this study is therefore to describe the quality rules practiced by eight Dutch general practice based registration networks and to explore how these rules fit the quality domains as established in the concept map. The fit of these quality rules is an indication of the internal validity of the concept map.

METHODS

We analyzed the quality rules of eight Dutch GPRNs by linking them to the quality domains of the concept map and to evaluate the quality domains as implemented in practice. We took the following steps: (1) we identified the applied quality rules concerning two selected disorders, (2) categorized them in the quality domains, and (3) evaluated the distribution of the quality rules over the quality domains in relation to the rated importance of the different domains.

Quality domains

The concept map was based on the question; "What determines good quality of data from general practice?" Five quality domains were identified and valued.[8] The importance of the domains and the statements within these domains were valued from 1 (low) to 5 (high). In order of general importance, the quality domains are "episode oriented recording" (3.36), "coding of information" (3.35), "complete health record" (3.16), "recording agreements" (3.01) and "diagnostic validity" (2.97), also see table 1.

"Episode oriented recording" includes the structuring frame of the information. The linking of different pieces of information (from e.g. different consults or diagnostic tests), concerning the same health problem, together to one episode of care. This also allows us to distinguish new from existing diagnosis, which is important for the estimation of incidence and prevalence figures. "Coding of information" refers to what information must be coded and linked in order to be included in the database. "Complete health record" contains quality rules about what 'additional information' must be recorded in EHR. 'Additional information' refers to information from medical specialists, a patient's medical history (after changing to another GP), contra-indications, and use of out-of-hour care. "Recording agreements" include network specific recording information, such as the interest in specific disorders, and to what extent the quality rules are known and applied in practice. "Diagnostic validity" relates to the true state of the patient; are all diagnostic codes correct and applicable to the individual patient?[8] To illustrate the domains, their most important underlying statements (rated ≥3) are included in table 2.

Participating networks

Eight of the eleven existing Dutch GPRNs participated in this research, the Academic Network of General Practitioners of the VUmc (ANH-VUmc), the Continuous Morbidity Registration Nijmegen (CMR), General Practice Network Academic Medical Centre (HAGnetAMC), the Netherlands Information Network of General Practice (LINH*), Registration Network Family Practices (RNH), the

Table 1 Rated importance of the quality domains by the individual GPRNs#

Network	Episode oriented recording	Coding of information	Complete health record	Recording agreements	Diagnostic validity
ANH VUmc	3.3	3.3	3.1	3.1	2.7
CMR	3.3	3.5	3.8	2.8	3.1
HAGnetAMC	3.0	2.3	3.4	3.3	3.2
LINH	3.5	4.1	3.7	3.2	3.0
RNH	3.9	2.4	2.8	3.1	3.4
RNUH	3.7	3.7	3.2	3.1	2.9
SMILE	3.3	3.0	3.0	2.6	3.3
TRANS	3.6	4.6	2.8	2.7	2.4
Total*	**3.36**	**3.35**	**3.16**	**3.01**	**2.97**

rated importance by the individual GPRN's representatives. * generally rated importance rated during the creation of the concept map. Score ranges from 1 (low) to 5 (high) importance, the quality domains rated >3.3 are considered to be more important and the quality domains rated <2.8 are considered to be less important.

Registration Network of General Practitioners Associated with Leiden University (RNUH-LEO), the Study of Medical Information and Lifestyle in Eindhoven (SMILE) and the Transition project (Trans). All GPRNs collect routinely coded data from general practices on a continuous basis, but there are also differences. For example, the number of listed patients covered ranges from 10,000 to over 350,000 patients per network. They also differ with respect to their primary goal: generating epidemiological information, providing a sampling framework for research, improving quality of care, and supporting education. Further information about these GPRNs can be found elsewhere.[5]

**LINH network is now called NIVEL-primary care database*

Selection of exemplary morbidity

We selected 'neck and back problems' and 'osteoarthritis' as two examples to describe the quality rules and evaluate these with the quality domains from the concept map. These disorders were selected because (a) general practice EHR data is an important source for the estimation of the incidence and prevalence rates of these disorders[9] (b). These disorders showed large variations between GPRNs, especially in prevalence figures. Furthermore, 'neck and back problems' are recurring diseases and often recorded using a symptom classification code, whereas 'osteoarthritis' is a chronic illness, with a specific disease classification code.[6]

Quality rules of GPRNs

We collected the rules of GPRNs about data recording, data processing and generating morbidity outcomes for the two disorders mentioned above using several steps.

- First, we collected the publicly available information about recording rules of all GPRNs. We structured this information in separate tables for neck and back problems and for osteoarthritis.

- Second, the coordinators of each GPRN checked and completed this information by answering five questions.
  a. Is there an operational definition of this disorder?
  b. Which classification codes are used to record this disorder?
  c. Which general and morbidity specific rules are applied to record this disorder?
  d. Are there any criteria or quality checks on the data entered in the database in general and/or regarding this disorder?
  e. Are there specific quality criteria, before certain data is available for research?
- Third, to complete the information the first author (CvdD) contacted each coordinator to clear all ambiguities.

The quality rules were categorized according to the quality domains of the concept map, with the help of the statements that were generated to construct the domains.[8]

Analysis

We evaluated the validity of the quality domains by considering the number of quality rules in each domain. Furthermore, we compared the distribution of the quality rules with the previously rated importance of the domains for each GPRN individually as well as with the overall importance score established in earlier research (Table 1).[8] The GPRN specific importance score of each domain was based on the average score of all statements within a specific domain rated by the GPRN's representative (on a 5-point Likert scale), see table 1. This rating was done in an earlier study[8], however, the individual scores of the GPRNs have not been published before.

RESULTS

Quality rules

All GPRNs indicated to acknowledge the general recommendations of the guideline "adequate recording of the electronic patient record (ADEPD)" from the Dutch College of General Practitioners to obtain a high-quality patient record for continuity and quality of care.[10] In addition, most GPRNs apply more strict quality rules in order to achieve a database with high quality.

The ADEPD recording recommendations are "structuring data in an episodes of care", "ICPC coding on each assessment part (SOAP-A-line) of the EHR", "recording at the true level of understanding", "record supplementary disorders in separate episodes of care" and "transition of episode title if objective information justifies the use of hierarchically higher diagnostic codes" (e.g. knee pain (ICPC code L15) should be adjusted to osteoarthritis of the knee (ICPC code L90) when X-ray and other additional symptoms (e.g. swelling, stiffness) justify this diagnosis). Furthermore, GPRNs accept the ADEPD discouragement of recording a "bulk episode (A99 or only chapter letters A to Z)" and "only recording journal data (no structuring of data in episodes of care)".

In addition to the ADEPD recording recommendations CMR-N, Transition and RNH apply more explicit quality rules, while ANH VUmc, HAGnetAMC, LINH, SMILE and RNUH allow more interpretation from

the GP. The CMR-N network instructs the participating GPs to record data about all contacts (home visits, telephonic consultations, contacts with practice assistant, incoming specialist letters and out-of-hour practice). Furthermore, diagnostic coding occurs only when the diagnosis is ascertained and GPs are discouraged to use a symptom code.

The participating practices of the Transition project use the second edition of the International Classification of Health Problems in Primary Care (ICHPPC-2) defined criteria (a classification system derived from ICD-9), which provides in- and exclusion criteria of diseases. Data about all contacts are linked to an episode of care, GPs need to check the existence of a similar symptom or complaint within the preceding three weeks and the EHR software system TransHIS© obstructs the creation of a new episode of chronic conditions if similar symptoms or complaints have been recorded before. Only one disease episode is created based on a medical specialist's report, regardless of how many health problems are indicated by the medical specialist.

The RNH network focusses on recording of episodes with an activation code (special attention status or episode-plus), also known as 'problem list'. A distinction is made between disorders that always need to be recorded and disorders that often need to be recorded as 'problem'. Disorders that demand regular care or are severe, such as diabetes mellitus or myocardial infarction, belong to the first group and chronic disorders without high care utilization or recurring disorders, such as osteoarthritis or chronic back pain, belong to the second group. Some health issues should not be recorded as a problem or as an episode-plus, such as a first appearance of back pain. GPs in the RNH network need to apply a comprehensive quality procedure before patient's are included in the central database; GPs need to check the patient's entire 'problem list', including the medical history and patient characteristics before a patient will be included in the database.

The principle of the LINH network is using ADEPD guideline, where GPs, if possible in their EHR, need to structure the data in episodes of care themselves. The RNUH network applies a similar approach. "The 'episode of care'-title needs to be changed if working hypothesis has changed" is a specific formulated RNUH quality rule. RNUH also includes a problem-list, with chronic, permanent or recurring diseases, which are not specified. SMILE conducts a more pragmatic approach, where the quality rules of the ADEPD guidelines are adapted to Medicom®, the EHR software package used in this GPRN. HAGnetAMC only includes disorders on the 'problem list' in the database, based on the ICPC-2 system with in- and exclusion criteria according to ICHPPC-2. Besides the application of the ADEPD guideline, the ANH VUmc GPRN emphasizes that "localization should be chosen over etiology when selecting a diagnostic ICPC code", "in case of surgery, the underlying disorder should be recorded". This network has a particular interest in anxiety, which includes recording of additional information on this subject ("ICPC anxiety codes (*25-27) are recorded in separate episodes of care").

Just a few specific rules are established by the GPRNs for neck and back problems or osteoarthritis. Some GPRNs apply strict ICHPPC-2 inclusion criteria for osteoarthritis: "Specific criteria of osteoarthritis, deformity on X-ray or functional disorder of at least 3 months with at least 3 other symptoms" (Transition, HAGnetAMC).

Categorization of quality rules

All GPRN quality rules were categorized in the five quality domains of the concept map, which represent aspects of general practice-based data quality, see table 2. The GPRN quality rules were matched to the original statements used to construct these domains (table 2 contains only statements with an importance score of 3 or higher). For example, the domain "complete health record" holds the statement "important information from a patient's medical history is transferred to the new EHR". An actual quality rule associated with this statement is "Information of new patients is considered new when firstly diagnosed after 6 months of entering the general practice" (HAGnetAMC). The quality rule "coding of most objective finding if diagnoses cannot be made" (ANH VUmc) relates to the statement "coding at the highest level of understanding" and quality rule "Including patient records in the database after full check of completeness of the problem list, including the medical history and patient characteristics" (RNH) is matched to the statement "All patients with an active diagnostic ICPC code actually have that disorder", both aspects of the "diagnostic validity" domain.

Evaluation of the quality rules

In total, we identified 68 unique quality rules. These are fairly distributed over the different quality domains. In general, more important quality domains include higher numbers of quality rules (table 3). This is also true when the seven general ADEPD quality rules are not included.

Furthermore, most important statements (rated ≥3) are linked to at least one quality rule (Table 2). The importance of each quality domain is not similar to all GPRNs (Table 1). For example, the Transition network rates "diagnostic validity" as less important whereas RNH and SMILE rate this specific domain as more important. The individual GPRNs showed only a small number of quality rules. Therefore a relationship between the number of quality rules and the importance of the quality domains could not be identified for the individual GPRNs.

DISCUSSION AND CONCLUSION

In general, a fair distribution of quality rules was found over the five quality domains, with a higher number of quality rules in the quality domains that are considered as more important. This suggests an acceptable internal validity of the established concept map.

Rosas and Kane[11] indicated that the internal validity of a concept map is often well addressed. This was also seen in this study, when merging all available quality rules of eight GPRNs together. There was not enough information available to investigate this to be true for all separate GPRNs, as quality rules of individual GPRNs did not cover the entire concept map. External validity of the five quality domains was not examined in this study.

Quality rules of individual networks do not cover all content of the quality domains. The coverage of the quality domains differs between individual GPRNs. This suggests that different GPRNs put

Table 2 Quality domains and the quality rules reported by the general practice recording networks

Quality domain	Statements of the concept map*	Quality rules
Episode oriented recording	No bulk episodes; individual complaints or disorders are recorded under different episodes of care	*All GPRNs reject the use of bulk episodes*
Structuring frame of health care information. Linking of information about the same health problem in episodes of care. Important to determine what health problems are current.	All episodes of care are (ICPC-)coded	Highest code is used as the episode title (LINH)
		Information system asks ICPC 'episode of care'-title (RNUH)
	Each sub-encounter is ICPC-coded and recorded under the correct episode	*Structuring of data in episodes of care*
		Only information that is linked to a episode of care is included in morbidity estimation (CMR-N)
	The problem list is accurate; all relevant health problems are recorded as an 'episode of interest' or are included in the problem list	Activation code in case of osteoarthritis is not obligatory (CMR-N)
		Recording significant health issues on problem list (HAGnetAMC,RNH,RNUH,SMILE)
		Recurring diseases explicitly formulated as occurring at least 3 times per 6 months or yearly (HAGnetAMC, RNH, SMILE)
	All sub-encounters are linked to an episode of care	Separate contacts are included in determination of morbidity figures (ANH VUmc, LINH, RNUH, SMILE)
	Complications of diseases are to be recorded as new episodes of care	Complications of chronic conditions need to be recorded separately (ANH VUmc).
	The ICPC codes of all episodes of care are kept up-to-date; changes are recorded	*Transition of episode title if objective information justifies hierarchical higher diagnostic codes*
		Change 'episode'-title from complaint to diagnosis, if justified (CMR-N)
		Spondylosithesis (L99) is hierarchical higher code than osteoarthritis (L84) (HAGnetAMC)
		Transitions are recorded, can appear as new problem (RNH)
		'Episode of care'-title needs to be changed if working hypothesis is changed (RNUH)
		The last given code of in an episode of care is valid for the whole episode (cannot be an lower code) (Trans)
	Co-morbidity is recorded in separate episodes of care	*Record supplementary disorders in separate episodes of care*
	Diagnoses not only as labelled disease but also as ICPC-coded episode of care	
	Episodes that can occur only once are registered only once	TransHIS prevents construction of a second episode of care for permanent or chronic disease-codes (Trans)
	The episode list is updated at every patient encounter	Episodes without an activation code end automatically (RNUH, SMILE)
	All problems or 'episodes of interest' are actively kept up-to-date regarding active and inactive status	Add activation code to episode of care if necessary (CMR-N)
	Each sub-encounter can be recorded under only one episode of care	Each incoherent complaint in one encounter must be recorded and coded separately (ANH VUmc)
	All referrals are linked to an episode of care	
	Recurring diseases are recorded in a new episode of care	Each encounter is recorded to be new or existing (CMR-N)
		Incidence figures of new patients are only included after 6 months of entering the practice (HAGnetAMC)
		Record the contact characteristic (new/ existing) in pop-up field (LINH)
		Contact characteristic (new/existing) recorded >75% (LINH)
		Consider identical complaints within 3 weeks to be one problem (Trans)

Quality domain	Statements of the concept map*	Quality rules
Coding of information	All assessment parts of SOAP include coded diagnosis	*GPs of all GPRNs need to use (ICPC-) codes*
		(ICPC) coding on each assessment part of SOAP
All important information is ICPC coded, not only as free text.		Coding of the underlying condition in case of surgery. (ANH VUmc)
		Coded contacts are included (ANH VUmc)
		New GPs; over 75% of the contacts are coded (ANH VUmc)
		General agreement 1: coding after certainty (CMR-N)
		E-list classification has limited complaint codes (CMR-N)
		Practices included if about 70% of the contact is coded (HAGnetAMC)
		More than 50% of all ICPC codes are recorded (LINH)
		TransHIS asks if a chronic code needs activation code (Trans)
		TransHIS gives an alarm when identical code is entered (even after 5 years) (Trans)
	Medication is linked to the right episode	
	All prescriptions are linked to a ICPC code	
	All referrals are allocated a (diagnostic) ICPC code	Referrals and diagnostic/ lab information are recorded (ANH VUmc)
		Always record after letter from specialist (CMR-N)
		Extra module of recording referrals to enhance recording (LINH)
		Always recording of an episode of care after receiving a specialist letter (Trans)
Complete Health Record	Information from out-of-hour practice is recorded	Home visits and information from out-of-hour practice are recorded in electronic health record (EHR) (CMR-N)
	Important information form patient's medical history is transferred to the new EHR	Information of new patients is considered new when firstly diagnosed after 6 months of entering the general practice (HAGnetAMC).
All 'external' information is recorded and available in the database. Including information from out-of-hour practice, referrals, medication etc.		Complete check of patient's EHR (also history) before a new patient is included into database (RNH)
	Information on multidisciplinary care is available in the GP information system	Coding after contact with practice assisted (CMR-N)
		Information with practice assistant is included (Trans)
	Data from medical specialist is entered into electronic medical record	GP records randomly discovered diagnoses to his best judgement (ANH VUmc, CMR-N, HAGnetAMC, LINH, RNH, RNUH, SMILE)
		Only one diagnoses from specialist letter is recorded (Trans)
	All contra-indications known to the GP are recorded in the patient's medical record	
	Encounter information is complete; all past encounters are recorded and visible in EHR	Additional recording information about anxiety, depression and venereal diseases (ANH VUmc)
	All lab results and measurements are recorded in diagnostic section of EHR	
	All medication is structurally recorded in the EHR	
	All referrals to primary and secondary care can be traced in the referral register or correspondence module EHR	
	Correct recording of medication status	
	All laboratory values are recorded in precise measurements	
	Causes of death are recorded	Recording of causes of death are monitored (CMR-N)

Quality domain	Statements of the concept map*	Quality rules
Recording agreements	Within a GPRN, there are clear unambiguous registration agreements, that are not multi-interpretable	Use "ICPC-anxiety (codes…25/26/27)" = fear for, concerns or questions about a type of illness. (ANH VUmc)
Network specific recording information and to what extent quality rules are known and applied in practice	Registration rules and agreements are well communicated and familiar to all practice team members	ADEPD guidelines specified for Medicom© (SMILE)
	GPs consult periodically about the quality of recording	Global check of volume monthly files (data delivery every month) (CMR-N)
	There are no big differences in recording quality between practice team members	Benchmarking between practices (RNH)
	There are clear registration agreements between practice team members	
	Regularly providing actual data (by appointment)	Episodes and contacts of the reference year are included (ANH VUmc, LINH, RNUH, Transitie)
		Episodes with activation code/ special attention status are also included in prevalence (CMR-N, SMILE)
		Only problems are included (HAGnetAMC, RNH, RNUH)
Diagnostic Validity	All patients with an active diagnostic ICPC code actually have that disease/disorder	
	Coding 'at the true level of understanding'	*Always record 'at true level of understanding'*
True health status of each individual patient. The ICPC codes are correct and applicable on the individual patient.		Localization (tractus) over etiology (ANH VUmc)
		Preferably no symptom diagnosis (CMR-N)
		Every code had in- and exclusion criteria (CMR-N)
		Questionable X-rays are coded as normal (HAGnetAMC)
	Coding 'at the highest level of understanding'	Coding of most objective findings if diagnoses cannot be made (ANH VUmc)
		L83 – includes complaints of neck, arms or headache caused by spine (HAGnetAMC)
	ICPC codes match the patients' conditions	Including patient records in the database after full check of completeness of the problem list, including the medical history and patient characteristics (RNH)
		Network specific in- and exclusion criteria of L-tractus (HAGnetAMC, Trans)
		Specific criteria of osteoarthritis; X-ray deformity or functional disorder (at least 3 months) and at least 3 symptoms (Trans, HAGnetAMC)
	Only valid use of classification categories 'others'; no escape codes are used	Adjustment of impossible or inconceivable codes (CMR-N)
	A sufficient number of ICPC codes is recorded; ICPC codes cover the entire encounter	

* The statements with a rated importance of 3 or higher are included in this table.
The italic quality rules are derived from the guideline "adequate recording of the electronic patient record (ADEPD)" from the Dutch College of General Practitioners.

Table 3 Number of practiced quality rules per general practice registration network categorized according to the domains of data quality

Network	Episode oriented recording	Coding of information	Complete health record	Recording agreements	Diagnostic validity	Total number of quality rules
ADEPD[*]	*4*	*2*	*0*	*0*	*1*	*7*
ANH VUmc	3[+]	4	2	2	2[^]	13
CMR	5[+]	3[+]	4[+]	2	3	17
HAGnetAMC	4	1[^]	2[+]	1	3	12
LINH	4[+]	2[+]	1[+]	1	0	8
RNH	3[+]	0[^]	2	2	1[+]	8
RNUH	5[+]	0[+]	1	2	0	8
SMILE	4	0	1	2[^]	0[+]	7
TRANS	3[+]	3[+]	2[^]	1[^]	2[^]	11
TOTAL (no duplicates)	**26**[+]	**15**[+]	**9**	**7**	**11**	**68**

Total of the quality rules in columns are all unique quality rules (without any duplicates), some GPRNs share the same quality rules. [*] ADEPD is the guideline "adequate recording of the electronic patient record" from the Dutch College of General Practitioners. [+] The more important domain; rated importance >3.3 out of 5. [^] The less important domain; rated importance <2.8 out op 5

different emphasis on the different aspects of the quality of their information. These differences might be closely related to the primary goal of the network. The primary goal of the GPRN to collect the data varies between GPRNs, as addressed before. Examples are: providing a sampling frame, educational purposes, or providing information for population health or for quality of care.

Our results are based on the selection of quality rules regarding the recording of neck and back problems and osteoarthritis. GP care for these disorders is usually rather straightforward. Recording agreements that are not essential for the recording of information for daily practice are relatively more sensitive to low recording quality and non-compliance to quality rules. This is also expressed in this research, which means that if such specific information is crucial for correct morbidity recording, other incentives may be necessary (e.g. payment) or additional effort needs to be invested in search of the missing information. The extent and nature of this missing information depends on the diseases studied. In our study, we investigated the existence of quality rules in the different General Practice Registration Networks. We do not have information on the extent of compliance of the participating GPs to these quality rules.

Strengths of our study include the comprehensiveness of the information regarding the existing quality rules, which was checked by the GPRN coordinators, and using two exemplary disorders in all GPRNs to make the information about the quality rules comparable. A weakness of our study is that the concept map was developed by experts from the same GPRNs. This underlines the necessity for external validation of the domains determining quality of general practice based morbidity data. Therefore, more research is needed to externally validate the concept map "quality of general practice based data".

We have some reservations whether the different sets of quality rules are sufficient for good data quality for the estimation of morbidity in the general population. Patients with substantial symptoms and complaints indicating the existence of osteoarthritis should be included in the prevalence estimations, regardless of year of occurrence or current treatment. Therefore it is important to systematically include an activation code (episode with attention status) and keep this up-to-date. In general, the quality rules established in the networks are not compulsory, which makes the data susceptible to variation.

Finally, more effort is needed to study the actual data quality of Dutch GPRNs regarding morbidity estimation. To be able to evaluate whether the quality rules are sufficient for good data quality it is important to have a complete overview of all quality rules. Furthermore, we need the information about the effects of the quality rules on the morbidity estimation and the compliance of GPs with the agreed quality rules.

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CHAPTER 7

General discussion

INTRODUCTION AND RESEARCH QUESTIONS

Morbidity rates are core indicators of population health and health care needs. Therefore, valid information about the incidence and prevalence rates of diseases is important. Policy makers need objective information about the health of the population to prioritize health problems, and to anticipate on trends in morbidity and health care needs in the future. Routinely recorded data from general practice is an important source to estimate morbidity in the population.

Especially in the Dutch healthcare system the general practice setting is promising in providing population data on morbidity. In the Netherlands patients are listed to a GP, regardless whether they need or use medical care. Furthermore, GPs fulfill the role as gatekeeper for secondary care, and basic health care insurance covers all general practice consultations. Therefore GPs have contact with all patients, without selection of age, gender, socio-economic status, ethnicity, and suffering from diseases in various stages of that disease.

General practice registration networks (GPRNs) gather routinely collected data from individual general practitioners (GPs) or practices. In the Netherlands, incidence and prevalence rates of many common diseases are estimated from GPRN data. However, the morbidity estimates derived from these Dutch GPRNs show considerable unexplained differences, which makes the interpretation of the figures difficult. We executed two steps to achieve a better understanding of the differences in morbidity estimations between various Dutch GPRNs.

1. Identification of factors that potentially influence the differences in morbidity estimations between GPRNs.
2. Analyzing the effects of these factors on the variation in morbidity estimation between Dutch GPRNs.

Knowledge on the effect of different factors that influence the variation in morbidity outcomes from general practice will contribute to qualitative better data to estimate population health.

MAIN FINDINGS; INTERPRETATION AND REFLECTION

1. POTENTIAL DETERMINANTS OF VARIATION

In this study, we identified four categories of factors (**chapter 2**) that potentially explain the differences in morbidity estimations provided by GPRNs; factors related to *patient characteristics (1), characteristics of the general practitioner and general practice (2), network methodology (3)* and *health care system (4),* see figure 1.

The chance of getting a disease is not equal for all people. Characteristics such as gender, age, socioeconomic status (SES), and ethnicity influence the probability to become ill.[1,2] Differences in *patient characteristics (1)* may be responsible for the variations in morbidity estimations between different GPRNs.

Earlier research showed that recorded information in general practice is influenced by *characteristics of the general practitioner and general practice (2)*.[3,4] The differences in, for example, recording discipline or recording preferences between GPs could lead to differences in morbidity estimations. These differences might be related to age and gender of the GP or to characteristics of the practice, e.g. practice size or type of electronic health record (EHR).

Network methodology (3) refers to the total of recording agreements of a GPRN; the operational definitions of diseases, the recording rules a GP needs to meet, the type of information collected, and the processing, storing, use and quality assurance of the data. These aspects determine what information is available and possibly contribute to the variation in morbidity estimations between GPRNs.

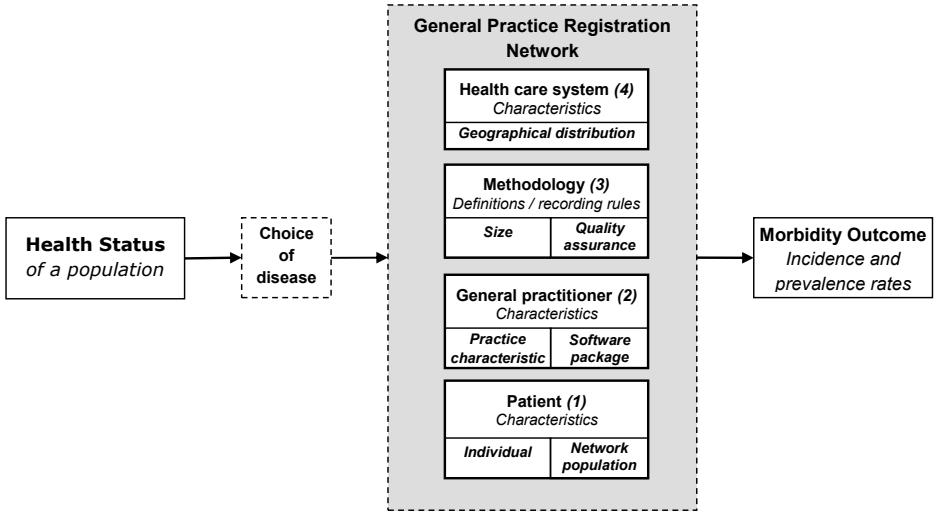

Figure 1 Factors influencing morbidity figures of General Practice based Registration Networks

The factor *health care system (4)* represents the differences in local, regional or national organization of healthcare as potential determinants of variation in GPRNs' morbidity estimates. Examples are the differences in accessibility of GP care, legislation, and health insurance policy.[5-8]

Choice of disease

The influence of the potential factors on morbidity estimations and the differences between GPRNs depend on the disease under study, see figure 1. The choice of disease could affect the results of the investigations and therefore we included a broad range of diseases in this study. In total, we explored the incidence and prevalence estimations of thirteen disorders. We included these diseases based on three criteria: (1) the expected occurrence of the disorder in the Dutch population should be at least 3 per 1000 per year, with preference for the more common diseases[3]; (2) a reasonable number of ICD classification chapters should be represented; (3) a variation of diseases, occurring in different subgroups in the population (different age groups, gender etc.).

General practice registration networks

In this research, we included eleven GPRNs that continuously record morbidity information, which is almost all GPRNs in the Netherlands. The GPRNs show considerable differences regarding all four categories of factors (**chapter 2**). The identified factors can theoretically explain (some of) the variation in morbidity estimations between GPRNs. The geographical coverage of the practices of the Dutch GPRNs varies from regional to national. The size of the GPRNs ranges from about 12,000 patients to one million patients, divided over eight to more than 360 GPs working in solo, duo or group practices. The main objective of the GPRNs differs, which can result in various methodological definitions and quality rules. Examples of main objectives are improving quality of care, generation of epidemiological data, providing a sampling frame for research, and to support education.

Morbidity variation between GPRNs

Overall, the incidence figures show relatively little variation between networks, especially in diseases with more clear diagnostic criteria (**chapter 3**), such as diabetes mellitus and herpes zoster. Lower variations of incidence rates suggest that health problems presented to general practice are comparable between GPRNs. Differences in prevalence figures are more substantial, especially in recurring diseases, such as neck and back problems or depression, and diseases with limited treatment options, such as osteoarthritis. To understand morbidity variations between GPRNs we investigated the possible explaining factors separately for incidence and prevalence figures.

2. ANALYZING THE EFFECT ON MORBIDITY VARIATION BETWEEN GPRNS

In this study we systematically analyzed the effects of the differences in patient characteristics, GP and practice characteristics, GPRN methodology and healthcare system on the variation in morbidity estimates between GPRNs. In this paragraph we summarize the study findings and reflect on these.

Patient characteristics

First, we analyzed the differences in population characteristics as a possible explaining factor for the variation in morbidity estimates between GPRNs (**chapter 3**). The distribution of age and gender was almost similar between GPRNs' populations, but considerable differences in SES, urbanization level and ethnicity have been observed. Our research showed that population characteristics are important for the estimation of morbidity, but they did not explain the variations in incidence and prevalence rates between the GPRNs that participated in our study.

Reflection on patient characteristics

The health care seeking behavior of patients is liable to change. There have been changes in care seeking behavior over time as a result of altered attitudes towards care. Research of Cardol and colleagues[9] showed a shift away from consulting a GP for minor ailments, such as sore throat or headache. Attitudes vary between different categories of patients. Older age, lower education, lower income, and non-Western background were associated with positive beliefs about the benefit

of consulting a GP for minor ailments.[9] Also the need for care alters during life; older people suffering from multimorbidity require more medical attention and the needed care is more complex, which can lead to differences in management and recording strategies, which can differ between GPs, general practices or GPRNs.

Characteristics of the general practitioner and general practice

We examined the influence of type of practice, percentage of female GPs, employment of a practice nurse, GP working experience, and distances to out-of-hour practice and nearest hospital (**chapter 4**). We found no indications that these factors were important for morbidity estimations. Only a small number of practice characteristics showed a significant influence on morbidity estimates for just a few diseases under study. For example, the employment of a practice nurse was associated with higher estimates of prevalence figures of chronic obstructive pulmonary disease (COPD), but not of other diseases. Adjusting for practice characteristics hardly reduced the variation between networks or practices. Characteristics of the GP or general practice did not explain the differences in incidence and prevalence figures between GPRNs.

The Dutch GPRNs use many different EHR software packages. We showed that in practices using the Medicom® package lower prevalence rates of diabetes mellitus, asthma, osteoarthritis, eczema, depression and anxiety were observed. Adjusting for the influence of type of EHR resulted in some decrease of the morbidity variations between practices. However, this trend was not seen in morbidity rates of two GPRNs exclusively consisting of practices using the Medicom® package. Therefore, we conclude that the EHR system did not explain the morbidity variations between networks. Recording strategies can attenuate the influence of the type of EHR.

Reflection on general practitioner and general practice

The GP characteristics were analyzed on the aggregated general practice level. It was not possible to analyze these characteristics on the individual GP level. Most patients cannot be related to a single GP, because patients are often treated by several doctors in one general practice (except for patients of single GP-practices). Research showed that GPs working together in the same practice show more similarities than GPs between practices.[3,4,10,11] Marinus[3] concluded that because of these resemblances the investigation of individual GP characteristics on variation would be less effective. Therefore, studying the influence of GP characteristics on general practice level was legitimate.

Network methodology

We studied the quality aspects of general practice based data and the quality rules of GPRNs as a part of the factor 'network methodology', which potentially can explain (part of) the variation in GPRNs morbidity estimates. The quality of the data requires special attention, as little is known about the actual quality of the data.

We explored (**chapter 5**) the conceptual ideas of representatives from ten Dutch GPRNs to identify common aspects of data quality. This resulted in a framework to define quality of general practice based data. Five content-based domains of quality were revealed. In order of importance, we

distinguished "episode oriented recording", "coding of information", "complete medical record", "recording agreements" and "diagnostic validity", see chapter 5 for more information about the quality domains.

We studied (**chapter 6**) the quality rules established by eight networks and compared them to the defined quality domains from the concept map. Overall, the total number of observed quality rules is fairly distributed over the domains. This suggests an acceptable internal validity of the established concept map. Individual GPRNs only use a small number of quality rules that do not cover all quality aspects. Therefore, some reservations have been made, whether the different sets of quality rules are sufficient for good data quality for the estimation of morbidity in the general population.

Reflection on methodology

The quality domains "episode oriented recording" and "diagnostic validity" are important for the estimation of morbidity. "Episode oriented recording (structuring of the data) is essential to differentiate between new (incidence) and existing (prevalence) disorders. "Diagnostic validity" (correct classification of a person's health problems) is important for the internal validity of the estimates. The relatively low evaluation of 'diagnostic validity' by the experts of the GPRNs is remarkable as quality of health care and a patient's well-being depend on receiving the right care for the right health problem. Diagnostic validity is also important for other aims of GPRN data, such as the provision of a sampling frame for research. Internal validation of diagnostic codes can be done combining more information from the EHR, such as referrals, diagnostics, and medication.[12,13]

We investigated the existence of quality rules, but not the compliance of GPs with the quality rules. The GPRNs expressed that recording rules that are not essential for daily practice are sensitive to non-compliance. Some of these recording agreements might be less important for daily care, but crucial for correct morbidity estimation. In these cases, other incentives may be considered (for example, payment).

In general, most GPRNs have no standard procedure to regularly check validity or the impact of missing values. Completeness can be assessed using the EPD-scan to benchmark the quality of recording to other Dutch GPRNs. The EPD scan includes indicators for e.g. the completeness of diagnostic coding and working with disease episodes.[14] Practices using the EPD scan showed increased figures in the following year, indicating that completeness is improved.[14]

The reason for data collection varies between Dutch GPRNs. The primary goal to collect data has consequences for the type of information available and for the requirements for the different aspects of quality (completeness, validity, reliability). This results in different operational definitions and quality rules. In this thesis, we were interested in the optimal requirements for measuring population health in terms of incidence and prevalence figures for important diseases. Only a small number of quality rules were found. Investigations have been made to include data of more consecutive years to exclude the missing of prevalent cases, which are diagnosed in earlier years, but did not receive an activation code. (Boshuizen, in preparation) This research showed that including data from three sequential years (instead of just one year) reduces the variation

in prevalence rates of diabetes mellitus, COPD, heart failure and osteoarthritis between GPRNs. However, still substantial differences exist. Possibly more sequential years must be considered, especially in disorders for which little care is necessary or available. Disease modeling, using the DisMod model, reduced the variation even more. This model uses all information on morbidity and mortality in each network to construct the most reliable estimations of prevalence and incidence rates. However, an assumption of this model is that the incidence of the disease is stable over time, but in studying population health, changes in incidence and prevalence are key points of investigation. These modeled incidence and prevalence figures should be interpreted with caution.

Despite the effect of including more years and modeling of the data, there still will be unexplained variation. The data of GPRNs is clustered in practices and in networks, which means that "respondents in the same cluster are likely to be more similar to one another".[3] Recording preferences for particular ICPC codes can bias the actual morbidity, resulting in an in- or decrease of estimated incidence or prevalence for certain disorders. The effect of these individual recording habits is larger in smaller networks compared to larger networks. Large GPRNs are less susceptible to chance (outliers), than small GPRNs. This may aim for the use of larger GPRNs. However, we do not know how much data is required and what the influence of size is on the quality of the data.

Health care system

The geographical distribution of all participating general practices within a GPRN can contribute to the variation in morbidity estimation. For example, the incidence of a myocardial infarction is significantly higher in Flevoland and Limburg.[15] Some Dutch GPRNs are nationally distributed, but most are situated in a smaller regions.

In the Netherlands, hardly any differences exist in the regulation of primary health care. One of the very few examples is that the distances to out-of-hour services or to a hospital are larger in more rural areas. Therefore, no large influence was expected by the factor health care system on morbidity estimates between GPRNs. We found only small regional differences in incidence figures of coronary heart disease, prevalence figures of diabetes mellitus, stroke, depression, and anxiety (**chapter 4**), but overall the effect of province could not explain any of the variation in morbidity estimates.

Reflection on health care system

The Dutch health care system has many advantages, but there are also challenges. General practice based databases only include information about morbidity if there has been contact with general practice for that specific health problem. This results in an underestimation of the actual morbidity in general population. The level of underestimation depends on a number of factors.

One of these factors is financially related. Financial incentives are known to change the behavior of patients and doctors and therefore change the information from general practice, and subsequently the morbidity estimations over time. If medication for a specific health problem is no longer reimbursed by insurance companies, less patients will visit their GP for that specific health problem.

For example, a strong decline in incidence rates of upper respiratory tract infection was observed in general practice after the exclusion of nose drops from the Dutch medicine reimbursement list.[16,17] In 2009, this was also seen that the exclusion of benzodiazepines from the Dutch reimbursement list resulting in a moderate decrease in incident rates of sleeping disorders.[18]

Another financial effect is that GP care is included in standard health insurance, but not all medication and diagnostics are included, at least until the own risk is paid (In 2015, a minimum is set at €375,-).[19] This may result in a reduced number of patients consulting a GP, leading to a higher underestimation of the morbidity in the total population. Furthermore, research of National General Practitioners' Association (Dutch: LHV, Landelijke Huisartsen Vereniging) showed that about 94% of the GPs deal with patients who disregard their advice due to financial barriers, 62% experience this weekly or even daily. This results, for example, in refusal of additional diagnostics.[20] In some cases a GP will not be able to make a conclusive diagnosis. This will probably lead to increased number of symptom codes, more uncertainty and higher variations. The effect of financial reimbursement may also vary between different socio-economic status (SES) patient groups.

Most problems are treated and solved in general practice.[21] When necessary, patients are referred to other health care professionals. However, there are some exceptions, for example, ophthalmologists and emergency care are directly accessible. In the past decennium, direct access has been increased, as physiotherapy and primary care psychologists became freely accessible. This may have led to lower morbidity estimations in general practice, especially of physical and psychological problems. Initiatives are being made to fill the gap by investigating and combining information of different primary health care professionals.[22]

IN SUMMARY

In summary, we found that three of the four factors studied in this thesis (patient characteristics, GP and practice characteristics, and health care system characteristics) did not contribute significantly to the explanation of differences in morbidity estimates between GPRNs. We assume that differences in the aims of GPRNs and, related to this, the differences in methodology, quality rules and compliance with these rules are the main determinants of the variation in morbidity estimates between GPRNs.

STRENGTHS AND WEAKNESSES OF THE STUDY

Broad overview population health

A strength of our study is the broad overview of different diseases investigated with respect to the morbidity variation between GPRNs. An incidence rate of at least 3 per 1000 per year was set according the analysis of Marinus[23], this number was implicated to be sufficient for analysis and further interpretation. Small prevalence estimations might be more susceptible to chance. We selected twelve disorders and we added herpes zoster as a thirteenth disease to this selection.

Fleming et al.[24] showed that the occurrence of this disease is very consistent in the population and therefore can be used as an indication of quality. The disease is painful, so patients seek medical care. Herpes zoster is easily diagnosed and is treated in general practice, which leads to low variations between populations. In our study, the incidence estimates of herpes zoster showed no significant variation between GPRNs and only small variations between practices, which indicate a fair to good quality of morbidity recording.

No information on external validity

A drawback of this study is that we did not investigate the external validity of the data of individual GPRNs, as the focus was on the variation between GPRNs. There is no golden standard available to compare the estimated morbidity from general practice to the 'true' frequency of the diseases. For some diseases, as cancer, there is a disease specific registry which is a valid and precise tool to measure incidence and prevalence. However, this would only give insight into cancer and we were interested a broad range of diseases to give a good overview of general population health.

Multi-level analysis using MOR (median odds ratio)

We used logistic multi-level models to investigate the influence of population and practice characteristics on the variation in morbidity estimates between networks and practices. Using this method, we were able to identify the unexplained variations in morbidity estimates on practice and network level separately. We calculated median odds ratio (MOR) as a measure to quantify the unexplained variation in morbidity estimates between GPRNs. MOR expresses that the risk of being diagnosed with a certain disease (i.e. diabetes mellitus) in one randomly chosen network is x times higher compared to another randomly chosen network.[25,26] A more familiar measure is intra class correlation (ICC), but this can only be estimated in continuous, normally distributed data, MOR is a dichotomy equivalent. The variations expressed in MOR have the advantage that they are directly comparable between diseases with different incidence and prevalence rates as occurrence rate has no influence on the magnitude of MOR. A relative disadvantage of MOR is that it is difficult to understand, as most researchers are unfamiliar with this measure.

Large general practice variation

This research showed large variations between general practices, which are sometimes larger than between general practice registration networks. These differences are independently interpretable as we used multi-level analysis. Morbidity figures from individual practices show much variation, probably due to individual recording habits of GPs. Population and practice characteristics did not explain the variation between practices. We did not investigate the intra-network variation (practice variation within one GPRN) to see whether practices within GPRN show more similarities than practices of different GPRNs. To account for the large differences between practices, a higher number of practices within a GPRN is preferred to compensate for possible outliers.

Common quality aspects

The construction of a collective concept map about aspects that are important in good quality of general practice based data is considered a strength of this study. The focus on the common aspects

is essential to comprehend each other's views and decisions for a better understanding of using GPRN data. The concept map showed a reasonable internal validity. However, the operationalization of the domains is different between GPRNs. This operationalization might be related to the aim of the specific GPRN. For example, to provide morbidity information more strict quality rules are necessary, than when the aim is to provide a sampling frame or for educational purposes.

CONSIDERATIONS AND IMPLICATIONS

General practitioners' first priority is to provide good quality patient care. GPs record the information about diagnoses in EHR for health care purposes. The structuring of this information gives an overview of the patients' health problems. For daily patient care, up-to-date, complete and valid information is necessary. GPs do not necessarily need uniformly coded information for good patient care. Therefore, quality of morbidity estimation based on GPRN data is not to be confused with quality of care.

This research contributes to a better understanding of the use of general practice based data for the estimation of prevalence and incidence rates of common disorders in the general population. This is important for external users of the general practice data, because it helps them to understand the value of the data for morbidity estimations (or for other purposes). This research also improved the communication between the different representatives of the GPRNs about the importance and possibilities of uniform data. Based on the findings and the discussion of this thesis we formulate several implications for users of general practice-based data for population health and for the GPRNs themselves. We end with suggestions for future research.

Implications using general practice based data for population health

To interpret morbidity data from general practice, a complex combination of factors need to be understood. Adjustment for population characteristics, age, gender, SES and ethnicity is important for valid morbidity estimation and therefore must be considered. We recommend anonymous linking of general practice based data to CBS data (e.g. income data) resulting in a more direct and precise measurement of SES. The practice characteristics, examined in this research, can be disregarded, because hardly any effects have been found.

The primary goal for data collection varies between Dutch GPRNs. The primary goal to collect data has consequences for the type of information available and for the requirements for the different aspects of quality. This results in a different set of operational definitions and quality rules for each individual GPRN. Therefore, it is important to know the primary goal of the GPRN and whether the most essential quality rules and definitions are met. Recurring diseases are more susceptible for the GPs interpretation and differences in recording agreements. Important is to explicitly formulate the definition of the disorder concerned and make clear what information is needed, as patients can recover from such disorders. For example, do you want to explore all episodes (with or without contact) or only a selection of all recorded episodes (with or without an activation code, e.g. only if there was any contact in the past five years for that specific disorder).

Implications for GPRNs

GPRNs are responsible for the internal quality of the data and the correct use of their data for other purposes, as the estimation of population health. GPRNs need to be aware of the possibilities and limitations of their data and should make this clear to the users of their data. A clear communication between the GPRN and the users is important, as both parties need to understand what information is needed and whether this information is available. Examples of the possibilities and limitations of the data is the proportion of missing data (% ICPC coded), diagnostic validity ("*all patients with an active diagnostic ICPC code actually have that disease"*), the quality of additional information (medication, referrals etc.) and the compliance with the agreed quality rules. Therefore, the establishment of a procedure to regularly check the quality of data on content is recommended.

Finally, joining forces between different GPRNs to provide the best morbidity estimates should be encouraged. This requires the use of compatible methods of morbidity estimation and enables comparisons of the data and enlarges the power of research. Uniform data collections can be facilitated by a uniform patient EHR. This enhances the linking of data from different health care professionals to create a complete picture. However, the development of such an EHR needs to be done in direct cooperation with GPRNs and participating GPs, as they have much experience with all the different aspects that need to be considered (functionality, recording issues etc.).

Further research

Little is known about the external validity of the morbidity figures of Dutch GPRNs. For most diseases no 'golden standard' is available to measure morbidity in the population. Investigating the possibilities and advantages of comparing and combining GPRN data with a variety of other data (e.g. other GPRNs, other primary care databases (physiotherapy, pharmacy etc.), disease registers, hospital admissions, insurance data, income data, death statistics, and health care interviews) is important to develop more knowledge about the validity of the morbidity estimates. Combining data will reduce missing diagnoses, but also reduce the missing's of contributing information (SES, medication use and treatment) and will make the data more uniform, which will enhance quality of morbidity estimations.

Furthermore, research should also investigate which quality rules are essential for estimating valid national morbidity figures and the relation between the primary goal of the GPRN data and the quality rules applied in the GPRN. This could be enhanced by the realization of a uniform EHR that allows GPs to optimal recording and researchers to optimal linking of information and to exclude variations based on software package. Finally, the compliance to the different quality rules and their influence on morbidity estimation should be investigated.

CONCLUSIONS

Morbidity registrations in general practice are very important sources of information for the estimation of incidence and prevalence rates of common disorders. We included almost all Dutch general practice registration networks (GPRNs) in our study. Morbidity estimations derived from these

GPRNs show considerable differences in the epidemiology of many diseases. The aim of this thesis was to contribute to a better understanding of the differences between Dutch GPRNs in incidence and prevalence figures of thirteen common diseases, and bring us closer to a qualitative better estimation of population health. Four groups of factors were considered; patient characteristics, characteristics of the general practice, health care system, and network methodology (definition and quality rules).

We found that the observed differences in morbidity estimations between the participating GPRNs cannot be explained by differences in characteristics of patients, general practitioners, practices characteristics or the health care system. Most likely, differences occur from differences in quality rules. These quality rules cover several important aspects relevant to the quality of the data: "episode oriented recording", "coding of information", "complete medical record", "recording agreements" and "diagnostic validity". The extent to which these domains are covered varies between the GPRNs, and is most likely dependent on the primary goal of the GPRN.

Future research should be aimed at the quality rules in relation to the primary goal. From the point of view of population health monitoring: What quality rules are most important for the reliability and validity of incidence and prevalence figures for common diseases?

This research contributes to the discussions on the use of data from general practice for different purposes. General practice registration networks need to take the possibilities and limitations of their data into account and consider whether their data is applicable for the estimation of national morbidity data. Possibly, cooperation and harmonization of data and/or an enlargement of a GPRN specialized in national morbidity estimation can enhance the reliability and validity of estimations of morbidity in the population.

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SUMMARY

Health policy makers need objective information about the health status of the population. Information about which diseases occur most frequently and which health problems deserve priority provides guidance to public health policy. Information on morbidity generated from general practices is an important source for data on the incidence and prevalence of common diseases.

The general practitioner (GP) is a core health care provider in the Dutch health care system and acts as a gatekeeper for specialist care. People are listed with a GP and basic health insurance is compulsory and identical to all citizens. In 2007, a no-claim premium was set, which later changed into a minimum mandatory deductible. However, GP care is exempted for this. As a result, general practice based morbidity data potentially covers the information of all patients suffering from diseases in various stages of their disease and of all patient groups without selection regarding age, gender, socio-economic status (SES) or ethnicity.

In the Netherlands, many GPs participate in a general practice registration network (GPRN). GPRNs collect anonymous patient information from the individual practices and collate the data in a (central) database for other purposes than daily patient care. Research of Gijsen and Poos (2006) showed that the morbidity estimations derived from five Dutch GPRNs show considerable unexplained differences in incidence and prevalence figures between networks.

The aim of this thesis is to contribute to a better understanding of the differences in incidence and prevalence figures between Dutch GPRNs, and contribute to a qualitatively better estimation of population morbidity. To do so, two steps are taken:

1. Identification of factors that potentially influence the differences in morbidity estimations between GPRNs.
2. Analyzing the effects of these factors on the variation in morbidity estimation between Dutch GPRNs.

1. POTENTIAL DETERMINANTS OF VARIATION

In **Chapter 2**, we provide a framework of factors that may explain the variation in morbidity estimations between GPRNs. These aspects are related to the levels of variation described by Marinus (thesis, 1993) (Country, region, practice, and doctor) and are translated to the GPRN situation. We identified four categories of factors; *health care system (1), network methodology (2), characteristics of the general practitioner and general practice (3) and patient characteristics (4)*.

The first category, the *health care system* refers to the differences in local, regional and national organization of healthcare. These aspects determine the accessibility of general practice and the rules or laws to which GPs have to comply. For example, restrictions in the access to healthcare limit the completeness of the information. Most healthcare characteristics are identical for an entire country, but some regional differences exist, such as distance to hospital and organization of out-of-hour services.

The second category of factors is *network methodology* of GPRNs. The operating definitions and registration rules affect the validity and reliability of the data for the estimation of morbidity. These aspects are related to the main purpose of the GPRN. Two specific factors described in this category are the quality assurance and the network size.

The third category is *general practitioner characteristics*, which includes all characteristics of the general practitioner (GP) and the general practice. Previous research showed less variation in contact frequency between GPs within a practice compared to GPs between practices. Examples of general practice characteristics are the number of GPs working in a practice, whether a general practice is incorporated in a healthcare center, and the employment of a practice nurse. Another important factor is the software package used to record patient information, the actual electronic health record (EHR), as previous research showed differences in consultation rates to be related to different EHRs.

The fourth category, *patient characteristics* is divided into individual patient characteristics (case mix) and the GPRN population as a whole. Patients differ from each other in many aspects, e.g. age, gender, SES, ethnic origin, and lifestyle. These aspects determine whether a person becomes ill, seeks help and contacts his or her GP. Furthermore, the representativeness of the GPRN population, in our case, the entire Dutch population, is important for the generalizability of the morbidity estimations.

2. ANALYZING THE EFFECT ON MORBIDITY VARIATION BETWEEN GPRNS

As a first step towards understanding the differences in morbidity estimations between Dutch GPRNs, we evaluated the GPRNs with respect to the identified variables (**chapter 2**). We selected eleven Dutch GPRNs who met two criteria; (1) the GPRN continuously collect data concerning all morbidity presented in general practice and (2) the GPRN is part of a long-term project. The Academic General Practice Network of VU University Medical Centre (ANH VUmc), Continuous Morbidity Registration Nijmegen (CMR), General Practice Network Academic Medical Centre (HAGnetAMC), Integrated Primary Care Information (IPCI), Netherlands Information Network of General Practice (LINH), Registration Network Groningen (RNG), Registration Network Family Practices (RNH), Registration Network of General Practitioners associated with Leiden University (RNUH-Leo), Study into Medical Information and Lifestyle (SMILE), Transition Project (Trans), and The Utrecht Network of General Practitioners (HNU) were included.

All GPRNs operate within the Dutch healthcare system. Therefore only limited differences regarding the health care system are expected. Some geographical differences may explain a part of the variation between morbidity estimations as most GPRNs cover only a small region. The main objectives of GPRN differ, examples are providing a sampling frame for scientific research, information about GP care, or GP-based epidemiology. Roughly, two types of data are considered; contact data and problem list data. GPRNs based on problem list data include only data of diseases that are permanent, chronic, or recurrent (HAG-net-AMC and RNH). Contact data based GPRNs

provide information of all health complaints, regardless of the severity of the problems (ANH VUmc, CMR, HNU, IPCI, LINH, RNG, and Trans). SMILE and RNUH-Leo include both types of data. In general practice, a lot of different software packages are operational. Most GPNRs consist of general practices with one or two types of software packages. To ensure a reliable and valid recording of diseases, different methods are used; training of GPs, explicit documentation (feedback), and GP meetings concerning registration difficulties and consensus procedures. The implementation of these quality aspects varies between GPRNs. The sizes of the GPRNs range from 13,500 to over 600,000 patients listed with 8 to 362 GPs in 3 to 80 general practices. The composition of the network patient population differs with respect to SES, ethnicity, and the level of urbanization. In addition, there are also differences in practice characteristics, such as practice size and the employment of a practice nurse.

In this thesis, we study the influence of patient population characteristics, GP and practice characteristics, network methodology issues and health care system factors. The GPRNs differ in these factors. Therefore they might explain part of the variation in observed morbidity between GPRNs. We do however not expect that the factors will explain all the differences, because the process of diagnostics is a complex interaction between knowledge, the wishes of the patient, the GP's judgement, and other factors.

In **Chapter 3** we investigated the influence of the differences in **population characteristics** between six Dutch GPRNs on the variation in incidence and prevalence of several disorders. We used episode based data of 2007 of a broad range of thirteen diseases. We excluded GPRNs which included only problem list data to rule out the differences due to different types of data. We studied the influence of age, gender, SES, urbanization level and ethnicity on the variation in incidence and prevalence estimates between general practices and GPRNs.

We calculated the median odds ratio (MOR) using the random intercepts of multilevel logistic regression analysis on general practice level and the network (GPRN) level. MOR quantifies the variation between clusters between two 'identical' persons from two randomly chosen, but different clusters and can be interpreted as the increased risk of being diagnosed with a particular disease comparing two randomly chosen GPRNs. We analyzed the effect of the population characteristics in three steps; variation between general practices and GPRNs without any explaining variables (empty model), variation adjusted for age and gender (model 1), and variation adjusted for age, gender, SES, level of urbanization and ethnicity (model 2).

No significant variation is seen in the incidence figures of diabetes mellitus, coronary heart disease (CHD), osteoarthritis, and herpes zoster. For example, the MOR of the incidence figures of herpes zoster was 1.08 (95%CI 1.00-1.34 in the empty model). Large variations (MOR>1.40) in incidence rates were seen in gastrointestinal tract infection, depression, anxiety disorders and chronic obstructive pulmonary disease (COPD), and in the prevalence rates of depression, anxiety disorders, stroke, CHD, COPD, dermatitis, osteoarthritis and neck and back problems. For example, the MOR of the incidences of depression was 1.49 (95%CI 1.14-3.05) and the MOR of the prevalence of

depression was 1.57 (95%CI 1.28-3.00). Overall, more variations were seen in prevalence figures than in incidence figures. Adjusting for patient characteristics did not explain the variations between GPRNs or practices as the MOR did not decrease in model 1 and 2 compared to the empty model.

In **Chapter 4** we investigated the influence of the different **GP and practice characteristics** on the variation in morbidity estimations general practices and GPRNs. We applied the same data analyses methodology as in chapter 3. We separately added type of practice, percentage female GPs, mean working experience, employment of a practice nurse, distance to nearest out-of-hours service location and distance to nearest hospital to the analyses. Hardly any of the GP and practice characteristics showed any significant influence on morbidity estimation. These characteristics neither explained any of the variation between networks.

We also studied the influence of the EHR software package and province on the variation between general practices in the LINH network, being the only network that included sufficient number of EHR types and operated nationally. EHR software package Medicom© was related with a lower estimate of the prevalence of 6 out of 10 diseases and the province "Groningen" was related with higher estimates in 3 out of 10 diseases. Still the effect on the variation between general practices was limited. For example, MOR changed from 1.71 (95%CI 1.59-1.90) to 1.65 (95%CI 1.54-1.82) in the prevalence of anxiety disorders. Additionally, the effect of Medicom© on morbidity estimations between GRRNs with only Medicom© practices and the other networks was not consistent. This suggests that recording strategies can alter the effect of the EHR software package regarding morbidity estimations.

In **Chapter 5**, we explored the conceptual ideas of the representatives of Dutch GPNRs on the quality of general practice based data, to identify common **aspects of qualitative good data** using the method of concept mapping. Ten experts of nine GPRNs participated in the brainstorm session. These experts generated 65 statements and seven were added based on literature, resulting in a total of 72 statements. These statements mainly contain aspects of the type of information that should be recorded and the manner this information should be structured.

Seventeen experts of the Dutch GPRNs rated the 72 statements on a 5-point Likert scale (1 = not important, 5= very important) and grouped them into meaningful clusters, based on meaning or similarity. A combination of principal component analysis and cluster analysis was used to represent the statements and clusters into a two dimensional picture; the cluster map.

A cluster map of six clusters was considered to be the best representation of the clusters generated by the experts, regarding representation of same conceptual ideas within a cluster and other conceptual ideas between the clusters. Five content based clusters (with rated importance based on the mean rate of the included statements per cluster) were found; complete health record (3.16), coding of information (3.35), episode oriented recording (3.36), diagnostic validity (2.97), and recording agreements (3.01). The sixth cluster was a residual category (2.46) without a recognized mutual content.

Chapter 6 describes the **quality rules** formulated by eight Dutch GPRNs and how these rules fit the quality domains as established in the concept map. We used neck and back problems and osteoarthritis as two examples. A total of 68 quality rules were identified and distributed over the five content based quality domains. The domains that were rated as more important, episode oriented recording (included 25 quality rules) and coding of information (included 15 quality rules) contained more quality rules than the lower rated domains. In general, a fair distribution of the quality rules over the quality domains was seen, as the most important aspects (rated ≥3 on a 5-point Likert scale) we covered, which suggests an acceptable internal validity. The individual GPRNs only showed a small number of quality rules (ranging from 0 to 5 individual GPRN quality rules per quality domain). A relationship between the number of quality rules and the rated importance of the quality domains could not be recognized. A drawback is that the concept map was developed by the experts from the same GPRNs, therefore, external validation of the domains will be important. The influence of the quality rules on morbidity estimates and the actual data quality of the different Dutch GPRNs need to be investigated in future research to understand the differences in morbidity outcomes between GPRNs.

DISCUSSION AND CONCLUSION

In **Chapter 7**, the main findings of this thesis were summarized and discussed, followed by methodological considerations, implications for users and providers of general practice based data, and suggestions for further research. The main result of our study is that characteristics of patients, GPs, general practices and the health care system did not contribute significantly to the explanation of differences in morbidity estimates between GPRNs. Differences in the primary goal of GPRNs and, related to this, differences in methodology, quality rules and compliance with these rules are most likely the main determinants of the variation in morbidity estimates between GPRNs. We identified five clusters of quality aspects. The quality rules practiced by GPRNs generally fit these quality domains: the more important domains contained more quality rules. The individual GPRNs showed a smaller number of quality rules, not clearly related to the importance of the domains. The influence of the quality rules on morbidity estimates and the actual data quality of the different Dutch GPRNs need to be investigated.

Quality of morbidity estimation based on GPRN data is not to be confused with quality of care. General practitioners' first priority is to provide good quality patient care for their practice population. GPs record the diagnostic information in the EHR for health care purposes. Using this information for the estimation of morbidity in the population, requires other criteria for recording than for health care only.

Based on these findings we formulated several implications for users and providers of general practice based data. We recommend to take population characteristics (age, gender, SES and ethnicity) into account when using GPRN data for population estimations for morbidity. Preferably by linking GPRN data to other sources to obtain more direct and precise measurements of SES and ethnicity. Practice

characteristics can be disregarded as hardly any effects on morbidity estimations have been found. The primary goal of a GPRN has consequences for the available data and for data quality. Therefore, both providers and users need to invest in understanding the essential quality rules and definitions and their potential effects on morbidity estimates. This is especially important in estimates of the prevalence of recurring diseases, such as depression and neck and back problems.

GPRNs need to be aware of the possibilities and limitations of their data and should make this clear towards the users of their data. We recommend a regular check of data quality on content (diagnostic validity, completeness etc.). Furthermore, joining forces between GPRNs to come to the best morbidity estimates should be encouraged. Uniform data collections can be facilitated by a uniform patient EHR, GPRNs as well as their participating GPs should participate in the development of such EHR, because they have much experience in the different aspects that need to be considered (e.g. function, recording issues).

Further research should investigate the external validity of Dutch GPRNs. For most diseases no perfect alternative is available to measure morbidity in the population, therefore possibilities and advantages of comparing and combining GPRN data needs to be examined. We recommend researchers to investigate the relation between the goal(s) of a GPRN and the operational quality rules. Also the compliance of GPs with these rules and the effect of the quality rules on morbidity estimation needs to be investigated. This research will further enhance the validity and reliability of data from general practice as a source for population health.

SAMENVATTING

Beleidsmakers hebben objectieve informatie nodig over de gezondheidstoestand van de algemene populatie. Informatie over welke ziekten het meest voorkomen en welke gezondheidsproblemen voorrang verdienen geven richting aan het volksgezondheidsbeleid.

De huisarts heeft een prominente rol in de Nederlandse gezondheidszorg als poortwachter van de zorg. Alle inwoners staan in principe ingeschreven bij één huisarts en zijn verplicht een gezondheidsverzekering af te sluiten. Daarbij is de basisverzekering identiek voor iedereen. In 2007 is een no-claim beloning ingevoerd, die in de jaren daarna is overgegaan in een verplicht eigen risico. Huisartsenzorg valt echter niet onder dit verplichte eigen risico. Deze kenmerken van de huisartsenzorg faciliteren de bruikbaarheid van informatie uit huisartsregistraties voor de schatting van morbiditeit, aangezien huisartsen informatie verzamelen over patiënten met allerlei ziekten in verschillende stadia, zonder selectie op basis van leeftijd, geslacht, sociaal economische status (SES) of etniciteit.

In Nederland nemen veel huisartsen deel aan een huisartsenregistratie (HAR). Deze HAR's verzamelen anonieme informatie over patiënten van individuele huisartsen of praktijken. Deze informatie wordt gebundeld in een (centrale) databank, waarbij deze informatie gebruikt wordt voor andere doelen dan de dagelijkse patiëntenzorg. Morbiditeitschatting is een van deze doelen. De morbiditeit die geschat wordt op basis van huisartsengegevens bevat alleen gezondheidsproblemen waarvoor mensen naar hun huisarts zijn gegaan is of die aan het licht zijn gekomen tijdens het bezoek aan de huisarts of andere zorgverlener. De geschatte morbiditeit is dus per definitie lager dan de werkelijke morbiditeit zoals deze voorkomt in de algemene populatie.

Het onderzoek van Gijsen en Poos (2006) laat zien dat er veel onverklaarde verschillen bestaan in de incidentie en prevalentie cijfers tussen verschillende HAR's. Het doel van deze studie is om bij te dragen aan een beter begrip van deze variatie, om uiteindelijke te komen tot kwalitatief betere schattingen van de morbiditeit in Nederland. Daarvoor hebben we twee stappen ondernomen:

1. Het identificeren van de factoren die mogelijk de verschillen in morbiditeitsschattingen tussen HAR's beïnvloeden.
2. Het analyseren van de invloed van deze factoren op de verschillen in morbiditeitsschattingen tussen Nederlandse HAR's.

1. POTENTIËLE DETERMINANTEN VAN VARIATIE

Hoofdstuk 2 geeft aan de hand van een model een overzicht van de potentiële determinanten, die mogelijk de variatie in morbiditeitsschattingen tussen HAR's verklaren. Deze aspecten zijn gerelateerd aan de niveaus van variatie (land, regio, praktijk en arts) beschreven door Marinus (thesis, 1993), waarbij we ze vertaald hebben naar de huisartsenregistraties. We onderscheiden vier categorieën van determinanten; gezondheidszorgsysteem, methodologie van de HAR, huisartskenmerken en patiëntkenmerken.

Het *gezondheidszorgsysteem* is gerelateerd aan verschillen in lokale, regionale en nationale organisatie van de zorg. Deze aspecten bepalen de toegankelijkheid van de eerste lijn en de regels of

wetten waaraan huisartsen zich moeten houden. Een voorbeeld is dat restricties in de toegang naar de zorg de compleetheid van de informatie beperkt. De meeste kenmerken binnen deze categorie zijn gelijk voor de onderzochte Nederlandse huisartsenregistraties. Wel zijn er enkele regionale verschillen, zoals de afstand naar het dichtstbijzijnde ziekenhuis of huisartsenpost.

De *methodologie* van de HAR, zoals de operationele definities en registratieregels, beïnvloedt de validiteit en betrouwbaarheid van de schatting van morbiditeit. Deze aspecten zijn gerelateerd aan de hoofddoelstelling van een HAR. Andere aspecten zijn grootte (steekproefomvang) en kwaliteitsborging.

Met de categorie *huisartskenmerken* worden alle kenmerken van de huisarts en de huisartsenpraktijk bedoeld. Eerder onderzoek heeft aangetoond dat er minder variatie in contactfrequentie bestaat tussen huisartsen binnen een praktijk dan tussen huisartsen van verschillende praktijken. Kenmerken van de huisartsenpraktijk zijn onder andere het aantal huisartsen binnen een praktijk, of de praktijk onderdeel is van een gezondheidscentrum en of er een praktijkondersteuner in dienst is. Een ander belangrijk aspect is het software systeem dat gebruikt wordt om patiëntinformatie in op te slaan, het elektronische patiëntendossier (EPD). Voorafgaand onderzoek toonde aan dat verschillen in contactfrequentie samenhangen met het type EPD.

Patiëntkenmerken zijn verdeeld in individuele patiëntkenmerken (case mix) en de HAR populatie in zijn geheel. Patiënten verschillen in leeftijd, geslacht, SES, etniciteit en leefstijl. Deze kenmerken bepalen mede of een persoon ziek wordt, hulp zoekt en contact opneemt met zijn of haar huisarts. Ook de representativiteit van de netwerkpopulatie voor in ons geval de gehele Nederlandse samenleving, is belangrijk voor de generaliseerbaarheid van de morbiditeitsschattingen.

2. ANALYSEREN VAN HET EFFECT OP DE MORBIDITEITSVARIATIE TUSSEN HUISARTSENREGISTRATIES

Als eerste stap in het begrijpen van de verschillen in morbiditeitsschattingen tussen huisartsenregistraties (HAR) hebben we aan de hand van de geïdentificeerde determinanten verschillende Nederlandse HAR vergeleken (**hoofdstuk 2**). We selecteerden HAR's op basis van twee criteria; (1) de HAR verzamelt continue gegevens van alle morbiditeit uit de huisartsenpraktijk en (2) de HAR neemt deel aan een lange termijn project. In totaal includeerden we 11 HAR's in ons onderzoek: Academisch Netwerk Huisartsgeneeskunde, Vrije Universitair medisch centrum (ANH-VUmc), Continue Morbiditeit Registratie Nijmegen (CMR), Huisartsen Netwerk Academisch Medisch Centrum (HAG-net-AMC), Integrated Primary Care Inforamtion (IPCI), Landelijk Informatie Netwerk Huisartsenzorg (LINH, nu: NIVEL zorgregistraties eerste lijn), Registratie Netwerk Groningen (RNG), Registratie net huisartspraktijken (RNH), Registratie Netwerk Universitaire Huisartspraktijken Leiden en omgeving (RNUH-Leo), Studie naar Medische Informatie en Leefwijzen in Eindhoven (SMILE), Transitie project (Trans) en Huisartsen Netwerk Utrecht (RNU).

Mogelijk kunnen geografische kenmerken een deel van de verschillen tussen HAR's verklaren. De meeste HAR's hebben immers een relatief beperkte geografische omvang. Alleen LINH* en IPCI zijn

nationaal verspreid. HAR's hebben verschillende primaire doelstellingen. Voorbeelden zijn het creëren van een wetenschappelijk steekproefkader, het verzamelen van informatie over huisartsenzorg of het verkrijgen van huisarts gebaseerde epidemiologie. Grofweg zijn er twee type gegevens; contact gebaseerde gegevens en probleemlijst gegevens. Probleemlijst gegevens bevatten alleen permanente, chronische of recidiverende klachten (HAG-net-AMC en RNH). Contact gebaseerde netwerken includeren gegevens over alle gezondheidsklachten, ongeacht de ernst van het probleem (ANH VUmc, CMR, HNU, IPCI, LINH, RNG en Trans). SMILE en RNUH-Leo hebben beide types van gegevens. In huisartsgeneeskunde zijn veel verschillende software systemen actief. De meeste HAR bestaan uit praktijken met één of twee type software systemen. Om te komen tot betrouwbare en valide registratie van ziekten worden verschillende methodes ingezet; training van huisartsen, expliciete documentatie (feedback) en huisarts bijeenkomsten over registratie moeilijkheden en consensus procedures. Deze zijn in meer of mindere mate geïmplementeerd door alle HAR. De grootte van de HAR's verschilt van 13.500 tot meer dan 600.000 patiënten, die ingeschreven staan bij 8 tot 362 huisartspraktijken. De samenstelling van de netwerkpopulatie verschilt in SES, etniciteit en urbanisatiegraad van de woonomgeving. Ook zijn er verschillen tussen praktijkkenmerken, zoals praktijkgrootte en het wel of niet in dienst hebben van een praktijkondersteuner.

In dit proefschrift willen we de invloed van patiëntenpopulatie, praktijkkenmerken, methodologische aspecten en de geografisch verdeling bestuderen. De HAR's verschillen in deze kenmerken, waardoor we verwachten dat de kenmerken op zijn minst een deel van de verschillen kunnen verklaren. We verwachten echter niet dat deze factoren alle variatie in morbiditeit zullen verklaren, omdat het diagnostisch proces een complexe interactie is tussen kennis, de wensen van de patiënt, de mening van de huisarts en andere factoren.

In **hoofdstuk 3** is de invloed van **populatiekenmerken** op de variatie in incidentie en prevalentie cijfers van verschillende ziekten tussen zes Nederlandse HAR's onderzocht. Er is gebruik gemaakt van een brede selectie van ziekten. HAR's met alleen probleemlijst gegevens zijn geëxcludeerd om de invloed van type data te reduceren. De invloed van leeftijd, geslacht, SES, stedelijkheid en etniciteit op de variatie in incidentie en prevalentie schattingen tussen huisartspraktijken en HAR's van dertien ziekten is bekeken.

De 'median odds ratio' (MOR) is op basis van random intercept op huisartspraktijk en netwerk niveau bepaald, gebruik makend van multilevel logistische regressie analyse op data uit 2007. MOR kwantificeert de variatie tussen clusters (in dit onderzoek de HAR's en praktijken) waarbij twee 'identieke' personen uit twee willekeurig geselecteerde, maar verschillende clusters met elkaar vergeleken worden. MOR kan uitgelegd worden als het toegenomen risico om gediagnosticeerd te worden met een specifieke aandoening. Het effect van populatie kenmerken is geanalyseerd in drie stappen; (1) variatie tussen huisartspraktijken en HAR's zonder verklarende variabelen, (2) variatie gecorrigeerd voor leeftijd en geslacht en (3) gecorrigeerde variatie voor leeftijd, geslacht, SES, mate van stedelijkheid en etniciteit.

Er is geen significante variatie gevonden in de incidentie van diabetes mellitus, coronaire hartziekten, osteo-artrose en gordelroos. Grote variaties (MOR>1.40) zijn gevonden in de incidentie van maag-

en darminfecties, depressie, angststoornissen en chronische obstructieve longziekten (COPD) en in de prevalentie van depressie, angststoornissen, beroerte, coronaire hartziekten, eczeem, osteo-artrose en nek- en rugklachten. Over het algemeen wordt er meer variatie tussen prevalenties dan tussen incidenties gevonden. De correctie voor patiëntkenmerken verklaarde niet de variatie tussen HAR's en praktijken, aangezien de MOR stabiel bleef na correctie voor populatiekenmerken.

In **hoofdstuk 4** is gekeken naar de invloed van **huisarts- en praktijkkenmerken** op de morbiditeitsvariatie tussen huisartspraktijken en HAR's. Dezelfde methode werd gebruikt als in hoofdstuk 3. Er werd steeds één van de volgende kenmerken toegevoegd aan de analyse; type praktijk (solo, duo of groepspraktijk), percentage vrouwelijke huisartsen, gemiddelde werkervaring, in dienst hebben van een praktijkondersteuner, afstand naar de dichtstbijzijnde huisartsenpost en ziekenhuis. Slechts enkele van deze kenmerken lieten een significante bijdrage aan de morbiditeitsschatting zien, maar geen van de kenmerken verklaarde (een deel van) de variatie tussen netwerken.

Ook is gekeken naar de invloed van type EPD en provincie tussen praktijken binnen het LINH netwerk. LINH is, in dit onderzoek, het enige netwerk met voldoende verschillende EPD's en een landelijke dekking. Er is een relatie gevonden tussen het EPD Medicom© en een lagere morbiditeitsschatting in 6 van de 10 onderzochte prevalente aandoeningen. In de provincie "Groningen" werd een hogere schatting van de prevalentie van 3 van de 10 onderzochte aandoeningen gevonden. Het effect op de variatie tussen praktijken was echter beperkt (MOR veranderde nauwelijks). De HAR's (RNUH en SMILE) die alleen gegevens verzamelen uit Medicom©praktijken laten over het algemeen geen lagere morbiditeitschatting zien ten opzichte van de overige HAR's met andere EPD's. Dit suggereert dat registratiemethoden het effect van het type EPD kunnen wijzigen.

In **hoofdstuk 5** wordt geëxploreerd wat de **kwaliteitsaspecten** zijn van een goede huisartsenregistratie voor de schatting van morbiditeit. Vertegenwoordigers van de verschillende Nederlandse HAR's hebben hun conceptuele ideeën hierover bij elkaar gebracht met behulp van de methode 'concept mapping'. Tien experts van negen HAR's namen deel aan de brainstorm sessie, waarbij 65 uitspraken over aspecten van kwaliteit gegenereerd zijn. Zeven uitspraken zijn toegevoegd aan de hand van bestaande literatuur. De statements gingen voornamelijk over welke informatie vastgelegd diende te worden en hoe deze informatie gestructureerd zou moeten worden.

In totaal zijn 72 statements op waarde beoordeeld en gegroepeerd in clusters, op basis van inhoud of overeenstemming. Middels een combinatie van principale componenten analyses en cluster analyse zijn de statements en clusters in een tweedimensionale grafiek gepresenteerd (=cluster map).

Het resultaat was een cluster map met zes clusters. De vijf inhoudelijke clusters zijn: compleet patiëntendossier, coderen van informatie, episode georiënteerde registratie, diagnostische validiteit en registratieafspraken. Het zesde cluster was een rest categorie zonder expliciete gezamenlijke inhoud.

Hoofdstuk 6 beschrijft de **kwaliteitsregels** van acht Nederlandse HAR's en hoe deze regels passen in de kwaliteitsdomeinen vastgesteld in de concept map. Algemene regels en regels rondom nek- en rugklachten en osteo-artrose dienden als voorbeeld. In totaal zijn 68 kwaliteitsregels geïdentificeerd

en verdeeld over de vijf inhoudelijke kwaliteitsdomeinen. De belangrijkere kwaliteitsdomeinen, episode georiënteerde registratie (25 kwaliteitsregels) en coderen van informatie (15 kwaliteitsregels), bevatten meer kwaliteitsregels dan andere kwaliteitsdomeinen. Over het algemeen waren de kwaliteitsregels redelijk verdeeld over de kwaliteitsdomeinen, waarbij de meest belangrijke aspecten gekoppeld konden worden aan één of meer kwaliteitsregels. Dit wijst op een acceptabel interne validiteit van de concept map. Er zijn echter onvoldoende kwaliteitsregels per individueel netwerk (0 tot 5 kwaliteitsregels per domein) gevonden om de clusters inhoudelijk te dekken. Een belangrijk nadeel van deze studie is dat de concept map ontwikkeld was door experts van dezelfde HAR's. Daardoor is het belangrijk om ook de externe validiteit te onderzoeken. Daarop volgend zou ook de invloed van de kwaliteitsregels en van de kwaliteit van de informatie van verschillende Nederlandse HAR's onderzocht moeten worden om verschillen in morbiditeitsschattingen tussen de netwerken te verklaren.

DISCUSSIE EN CONCLUSIE

De conclusie van het onderzoek, zoals beschreven in **hoofdstuk 7,** is dat drie van de vier factoren, die bestudeerd zijn in deze studie (patiëntkenmerken, huisarts en praktijkkenmerken en het gezondheidssysteem) geen significante bijdrage leveren aan de verklaring van verschillen in morbiditeitsschattingen tussen HAR's. De verschillen in doel en de hieraan gerelateerde verschillen in methodologie, kwaliteitsregels en de naleving van deze regels zijn naar alle waarschijnlijkheid belangrijkere determinanten voor de verklaring van de verschillen in morbiditeitsschattingen tussen HAR's. In dit proefschrift hebben we geëxploreerd wat HAR's verstaan onder kwaliteit en welke kwaliteitsregels zij hanteren. De volgende stap is om de invloed van deze regels op de morbiditeit te onderzoeken.

Kwaliteit van morbiditeitschatting dient niet verward te worden met kwaliteit van zorg. Voor de huisarts heeft het geven van kwalitatieve zorg aan zijn of haar patiënten de hoogste prioriteit. Het registreren van diagnostische informatie in het EPD is dan ook primair bedoeld voor dit doel. Het gebruik van deze informatie voor morbiditeitschatting in de algemene populatie vereist echter ook andere criteria.

Op basis van deze bevindingen hebben we nog een aantal consequenties benoemd voor het gebruik van HAR-gegevens voor de bepaling van morbiditeit in de algemene bevolking. Zo dienen de populatiekenmerken meegenomen te worden, bij voorkeur door het linken van HAR-gegevens aan andere bronnen, die meer directe en precieze metingen van populatiekenmerken als sociaaleconomische status en etniciteit bevatten. Praktijkkenmerken kunnen buiten beschouwing gelaten worden, aangezien het effect op de morbiditeitschattingen verwaarloosbaar klein zijn. De hoofddoelstelling van een HAR heeft consequenties voor de beschikbaarheid van de gegevens en voor de kwaliteit ervan. Het is belangrijk dat niet alleen de HAR's zelf maar ook gebruikers investeren in het identificeren en toetsen van essentiële kwaliteitsregels voor het doel waarvoor de gegevens gebruikt worden.

HAR's moeten zich bewust zijn van de (on)mogelijkheden van hun data en dit kenbaar maken aan de gebruikers van deze data. Onze aanbevelingen zijn om de data regelmatig op kwaliteit en inhoud te beoordelen (diagnostische validiteit en compleetheid). Verder stimuleren we de bundeling van krachten tussen HAR's. Het gebruik van data voor morbiditeitschatting is gebaat bij uniforme morbiditeitsgegevens, bij voorkeur gefaciliteerd door een uniform patiëntendossier (EPD). HAR's en hun deelnemende huisartsen kunnen een belangrijke rol vervullen in de ontwikkeling van zo'n EPD door hun uitgebreide ervaring en kennis omtrent registreren van morbiditeit.

Verder onderzoek dient zicht te richten op de externe validatie van data uit HAR's. Voor de meeste aandoeningen geldt dat er geen gouden standaard beschikbaar is om de morbiditeit in de algemene populatie te meten. Daarom is het belangrijk om de mogelijkheden en voordelen van vergelijken en combineren van verschillende gegevensbronnen te onderzoeken. Ten slotte, zou onderzoek zich nog moeten richten op de invloed van het primaire doel van een HAR op de operationele kwaliteitsregels, de naleving van de regels door de deelnemende huisartsen en het effect van de verschillende kwaliteitsregels op de morbiditeitsschatting.

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Karin

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Karin van den Dungen was born on June 10th 1980 in Valkenswaard, the Netherlands. In 1999 she completed pre-university-education at the St-Joriscollege in Eindhoven. That same year she started her study Health Science with specialization Movement Science in Maastricht. After three years she combined this study with studying Physiotherapy at Hogeschool Zuyd in Heerlen. She graduated from both studies in 2006. After graduation she continued to work as a research assistant at Maastricht University, where she co-operated in a randomized controlled trial about the effect of regular water intake in patients with recurrent headaches. Later that year she started working as a physiotherapist at rehabilitation center Breda. In February 2007 she started her PhD project at department Tranzo at Tilburg University and at RIVM. She conducted her research on explaining variations in morbidity estimates between general practice registration networks. Karin is currently active at Avans+ as a lecturer in the Master's program physiotherapy. Karin is married to Stijn Verhagen and they have one daughter named Juul (2013).

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