

# Computerized health information in the Netherlands: a registration network of family practices

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**SUMMARY.** A registration network of family practices (Registratienet Huisartspraktijken) has recently been established in the Netherlands. Forty two general practitioners in 15 practices, with a patient population of 80 000 people, are using a general practice health information system to establish a central computerized anonymous database containing certain patient characteristics and all relevant health problems. By September 1990 patient characteristics and problem lists for 32 972 patients had been entered and a total of 94 476 health problems had been identified. The database has been set up primarily as a sampling frame, allowing researchers to identify patients with particular health problems. The database can also provide descriptive data on prevalence and incidence rates, fulfil a monitoring function and provide data for practice audit, medical education and health management.

**Keywords:** GP research organizations; sentinel GP; information systems; Netherlands.

## Introduction

GENERAL practitioners possess a wealth of information on the health of their patients, and on many aspects of their medical treatment. Hence, they are in a unique position to gather information for research, education or management. Research in the primary care field is not easy, but its need and feasibility were clearly stated by Backer.<sup>1</sup> He also addressed the paradox between large research projects which often produce statistically significant results but of low clinical significance, and small studies, which tend to produce a better quality of information but where the number of subjects involved is too small to allow generalization.

A solution to this paradox would appear to be collaborative research.<sup>2</sup> This approach has been successfully carried out in the United Kingdom where many health problems have been studied using data gathered in the national morbidity surveys undertaken by the Royal College of General Practitioners.<sup>3</sup> Surveillance of common infectious diseases is carried out by practices participating in the weekly returns service or similar

networks such as the Oxford regional sentinel practice scheme.<sup>4,5</sup> Van Casteren recently published an inventory of sentinel health information systems involving general practitioners in the European Community revealing that sentinel networks have been established in almost all European countries.<sup>6</sup> There are, however, great differences between the networks in respect of organization, purpose, registered health problems and functioning. The goal of the collaboration may be to study morbidity in general practice, to undertake surveillance of certain (communicable) diseases, or to keep track of trends in general practice. The Dutch sentinel practice network is an example of such a registration network.<sup>7</sup> Other practice networks, whether small like the Missouri network or large like the Ambulatory Sentinel Practice Network, collaborate to answer research questions.<sup>8,9</sup>

A registration network of family practices (*Registratienet Huisartspraktijken*) was established in the Netherlands in 1988. Health problems and diagnoses in general practice are recorded and registered on a central database which can support research and educational programmes. This paper summarizes the objectives of the network and the methods used, describes the data obtained and discusses the research potential of this data.

## General practice as a source of information

The general practitioner plays a vital role in the Dutch health care system. General practitioners are the only physicians working in primary health care and are, therefore, the route into the medical system. They occupy a 'gate keeper function' which implies that, in principle, all referrals to other specialists take place via them. Furthermore, nearly all patients are registered with a general practitioner, whether they are insured by sickness funds or are private patients.

Most of the health problems presented to general practitioners are not seen by specialists and therefore general practices are important sources of information. This information is generally stored as handwritten records, and is not always easily accessible for research purposes. The use of computerized records in general practice facilitates the accessibility of this health information.

## Registration network of family practices

The chief goal of the registration network of family practices is to establish a computerized anonymous database containing certain patient characteristics and all relevant health problems. The database has been set up primarily as a sampling frame, allowing researchers to identify patients with particular health problems or combinations of problems. This means that there are distinctive differences between the design of this registration network and that of morbidity studies, as the latter include only morbidity. On 1 September 1990, the registration network of family practices consisted of 42 participating general practitioners in 15 practices. Thirteen practices are located in the southern part of the province of Limburg, within 30 kilometres of the University of Limburg, while the remaining two practices are situated further to the north, 70 kilometres from the univer-

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sity. The population covered by these 42 general practitioners is approximately 80 000 patients.

In all participating practices computerized health information systems were installed, replacing the handwritten records. Data on patient encounters and other health information are stored on the computer. On a daily basis, the general practitioners complete the records of several patients, by adding patient characteristics and revising the problem list. It was stipulated that the general practitioners should not develop a specific pattern such as first completing the records of elderly patients or patients with asthma, but should 'randomly' select patients. Once completed, the data for a patient is kept up to date. Every three months these data are made anonymous and transferred by floppy disc to the Medical and Social Information Center at the University of Limburg, where they are fed into a database.

The following patient characteristics are transferred to the database: practice code (unique code identifying the practice); physician code (unique code identifying the physician); patient identification (unique internal code of the health information system); household identification (identifies all persons belonging to the same household); sex; date and place of birth; marital status; type of household — couple, family, and so on; place of residence and postal code; date of entry to the practice; date of update; insurance status; date and reason for leaving the practice; and level of education.

All relevant health problems must be included on the problem list, as it is an essential part of the medical record. A health problem is defined as 'anything that has required, does or may require health care management and has affected or could significantly affect a person's physical or emotional well-being'.<sup>10,11</sup> This definition requires the following types of problems to be included: diagnoses, such as diabetes mellitus; patterns of complaints, such as chronic low back pain; abnormal findings, such as abnormal electrocardiograph; risk factors, such as alcohol abuse; and other problems, such as adverse effects of a medical agent.

Problems are recorded if they affect the present functional status of patients and/or their future functioning. Thus, only permanent problems (no recovery expected), chronic problems (duration longer than six months), and recurrent problems (more than three recurrences within a six month period) are included on the problem list. Problems are stated at the highest level of refinement which can be reasonably defended, that is, a condition cannot be given two problem definitions at the same time, such as low back symptoms and osteoarthritis of the spine. All problems are coded using the *International classification of primary care (ICPC)*.<sup>12</sup> The recording of a recently established diagnosis is justified if the inclusion criteria of the *International classification of health problems in primary care (ICHPPC-2 defined)*<sup>13</sup> are met, but criteria are only available for a limited number of ICPC codes and mainly for diagnoses. Otherwise, the complaint or syndrome is recorded. Past diagnoses recorded in the patient's notes are accepted without checking ICHPPC criteria, since details of the medical history are no longer available in many cases.

Problems are characterized as 'active' or 'inactive'. A problem is considered to be active if it has the attention of the general practitioner or the patient at that moment, as shown by present treatment (diet, medication or specific therapy), further diagnostic investigations, regular checks for that problem or a known progressive course of a disease.

The following data are transferred to the database for all problems: health problem (ICPC code); problem status (active or inactive); and date the problem became active or inactive.

More detailed instructions have been formulated for the

general practitioners. These are given in a registration handbook which is regularly updated.

### Quality control

The health information software provides the general practitioner with an automated thesaurus for the *International classification of primary care* and displays ICHPPC criteria for the ICPC code, when available. The quality of the data recorded should thus be enhanced by this software. The software also checks for erroneous or missing entries before the data is transferred to the central database. Moreover, the age and sex distribution of the patients registered on the network are compared with that of the whole practice, in order to check the representativeness of the database.

Aspects of problem definition and coding are discussed in 'consensus groups'. Five such groups, of about eight general practitioners each, have been formed, meeting four or five times a year. In addition to this process of peer review, which is highly appreciated by the participating practitioners, the staff of the network use these meetings to determine the consistency with which general practitioners define and code problems.

Feedback from the Medical and Social Information Center is also part of the quality control programme. Omissions, inconsistencies and mistakes are reported to the general practitioners and staff of the network. The updates to the instructions for the general practitioners cover these quality control efforts.

### General data held on the database

On 1 September 1990 patient characteristics and problem lists for 32 072 patients had been entered in the database. Approximately 4500 patients are added every three months, which means that the register should be complete by the end of 1993.

The patient characteristics of the registered patients are given in Table 1. The patient population of the network resembles the general population of the Netherlands with respect to age, sex, marital status, type of household, insurance status and level of education. A total of 94 476 problems have been identified for these patients; 50 488 (53.4%) active and 43 988 (46.6%) inactive. The distribution of male and female patients in the database is almost equal (48.2% versus 51.8%), but only 44.8% of the problems are experienced by male patients. Thus, overall women have more problems per person than men (3.1 versus 2.7) (Table 2). Table 2 also shows that below the age of 15 years male patients have more problems per person than female patients, but that from the age of 25 years and over that trend is reversed. This is also true for active problems. Furthermore, only 17.3% of the patients have no health problems on their problem list (18.1% of male patients and 16.6% of female patients).

The distribution of problems between the ICPC chapters is shown in Table 3. Health problems and diagnoses related to the musculoskeletal system rank highest, followed by respiratory, circulatory and digestive system problems. These four chapters include almost 50% of all registered health problems and diagnoses. The 20 most frequent active and inactive problems, for male and female patients, are given in Table 4. The general picture which arises from the most common active problems is not surprising: hypertension; diabetes mellitus; lung problems such as asthma and chronic bronchitis; back problems; and risk factors such as smoking and obesity. Striking is the position of adverse effects of medication in a proper dose; health care itself apparently produces frequent problems. The inactive problems listed may not appear very interesting but these problems account for 46.6% of all problems and therefore provide researchers with an opportunity to define patient groups with particular health problems that have already been treated.

**Table 1.** Characteristics of the 32 072 patients registered on the database on 1 September 1990.

	% of patients
<b>Sex</b>	
Male	48.2
Female	51.8
<b>Age (years)</b>	
0-4	6.5
5-14	11.8
15-24	14.1
25-44	33.5
45-64	20.7
65-74	8.4
75+	5.1
<b>Marital status</b>	
Married	48.5
Divorced	2.7
Single	38.7
Cohabiting	3.3
Widow(er)	5.4
Other	1.3
Unknown	0.2
<b>Type of household</b>	
Couple	18.5
Family	63.2
One parent family	4.2
Single person	10.5
Family/couple with lodger(s)	1.4
One parent family with lodger(s)	0.3
Single person with lodger(s)	0.7
Home for the elderly	0.9
Commune	0.2
Other	0.1
Unknown	0.2
<b>Insurance status</b>	
Sickness fund	67.3
Private insurance	32.7
<b>Level of education<sup>a</sup></b>	
Low (primary education/lower vocational training)	55.8
Medium (secondary education)	34.0
High (higher education)	10.0
Missing data	0.2

<sup>a</sup> For the 21 679 patients aged 25 years and over.

**Table 2.** Mean number of problems and of active problems per person by sex and age group.

Age (years)	Mean no. of problems per person		Mean no. of active problems per person	
	Male patients	Female patients	Male patients	Female patients
0-4	0.8	0.6	0.5	0.4
5-14	1.6	1.4	0.7	0.6
15-24	1.9	1.9	0.8	0.9
25-44	2.4	2.9	1.2	1.4
45-64	3.8	4.3	2.1	2.3
65-74	5.0	5.2	3.0	3.2
75+	5.7	6.2	3.5	4.1
Total	2.7	3.1	1.4	1.7

### Use of the database

The database has been set up primarily as a sampling frame, allowing researchers to identify patients with particular health problems or combinations of problems. Descriptive studies and

**Table 3.** Distribution of problems between the *ICPC* chapters.

<i>ICPC</i> chapter	% of problems (n = 94 457)
A General and unspecified	6.5
B Blood, blood-forming organs, lymphatics, spleen	0.7
D Digestive	9.8
F Eye	2.5
H Ear	3.6
K Circulatory	9.9
L Musculoskeletal	17.1
N Neurological	4.0
P Psychological	6.1
R Respiratory	11.6
S Skin	6.0
T Endocrine, metabolic and nutritional	4.5
U Urology	2.6
W Pregnancy, childbearing, family planning	4.0
X Female genital system (including breast)	5.5
Y Male genital system	2.8
Z Social problems	2.9

n = total number of problems. Data missing or inadequately coded for 19 problems.

quality assurance studies can easily be performed and study and control groups can be assembled for various study designs, such as clinical trials, cohort studies and case control studies. The following projects have used the network database for the identification of a study population: studies of blood glucose regulation of patients with non-insulin dependent diabetes mellitus;<sup>14</sup> diagnoses of cancer in the registration network of family practices and at the district cancer service of the Limburg Integrated Cancer Centre; use of diuretics in elderly patients with oedema of the ankle in general practice; somatization in daily life; adverse effect of medical agents used in the proper dose; and relationship between sterilization and vaginal extirpation of the uterus. The database can provide descriptive data on prevalence and incidence rates. Since problem lists are entered with patient characteristics, all variables can be used as the nominator or denominator. The point prevalence of a problem is the frequency of that problem in the registered patient population at a certain date. The incidence of a problem can be calculated as the frequency of new entries for a certain problem per 1000 patients per year. Incidence and prevalence should, however, not be confused with active and inactive. When calculating the incidence, only problems which have been both new and active in a certain year will be counted. For the prevalence rate it is not relevant whether the problem is active or inactive.

Comparison of this data with data from morbidity studies should be carried out carefully as the registration network of family practices has not been set up as a morbidity study. The problem definition used in the network excludes minor self limiting diseases. Hence, the top 20 active problems give no indication of what general practitioners see most commonly in their daily practice nor how often they see certain patients. However, the database does indicate how many patients have one or more serious health problems which influence their well being. Differences between the prevalence rates for particular diseases such as hypertension and asthma determined from the database and from morbidity studies are partly the result of the problem definition used for the database, which states that problems are only to be registered if they have or may have consequences for the functional status of the patient and if the problem is permanent, chronic or recurrent. Another reason for the difference may be that diagnoses established in the past were accepted for the database problem list without checking that the *ICHPPC* criteria were fulfilled.

Table 4. Twenty most frequent active and inactive problems.

ICPC code		% prevalence		
		All patients (n = 32 072)	Male patients (n=15 458)	Female patients (n=16 614)
<i>Active problems</i>				
P17	Tobacco abuse	9.2	10.8	7.7
A85	Adverse effect medical agent proper dose	8.3	5.3	11.1
K86	Uncomplicated hypertension	5.4	4.0	6.7
R96	Asthma	3.7	4.1	3.3
R97	Hayfever, allergic rhinitis	3.5	3.7	3.3
T90	Diabetes mellitus	2.7	2.2	3.2
T82	Obesity (BMI > 30)	2.6	2.0	3.2
P01	Feeling anxious/nervous/tense/inadequate	2.4	1.7	3.1
L03	Low back symptoms/complaints without radiation	2.3	2.8	1.9
S87	Atopic dermatitis/eczema	2.2	2.1	2.4
L86	Lumbar disc lesion, back pain with radiating symptoms	2.0	2.3	1.7
A12	Allergy/allergic reaction not otherwise specified	2.0	1.9	2.0
L84	Osteoarthritis of spine (any region)	1.9	1.7	2.1
K95	Varicose veins of leg	1.9	0.7	3.0
T83	Overweight (BMI <30)	1.8	1.6	2.0
H86	Deafness/partial or complete not elsewhere classified	1.8	2.0	1.6
L90	Osteoarthritis of knee	1.7	1.2	2.2
R91	Chronic bronchitis/bronchiectasis	1.7	2.0	1.4
L98	Acquired deformities of limbs	1.7	1.5	1.8
S88	Contact dermatitis/other eczema	1.5	1.1	2.0
<i>Inactive problems</i>				
R90	Hypertrophy/chronic infection tonsils/adenoids	7.1	7.2	7.0
D88	Appendicitis	3.3	2.8	3.7
D89	Inguinal hernia	2.5	4.2	0.9
L76	Fracture: other	2.4	2.7	2.1
Y13	Family planning/sterilization	2.3	4.8	—
W92	Complicated delivery liveborn(s)	2.3	—	4.4
D98	Cholecystitis/cholelithiasis	2.2	0.9	3.4
W13	Family planning/sterilization/referral for	2.2	—	4.2
L99	Other disease musculoskeletal system/connective tissue	2.0	2.1	1.9
L86	Lumbar disc lesion, back pain with radiating symptoms	1.9	2.3	1.5
L72	Fracture: radius/ulna	1.8	1.6	2.0
X78	Fibroid/myoma (uterus/cervix)	1.7	—	3.2
U95	Urinary calculus all types/sites	1.6	2.1	1.0
L96	Acute damage meniscus/ligament of knee	1.5	2.3	0.7
D99	Other diseases digestive system	1.4	1.4	1.5
X99	Other diseases female genital system	1.4	—	2.7
L73	Fractures: tibia/fibula	1.4	1.8	1.0
W82	Abortion, spontaneous	1.3	—	2.5
K95	Varicose veins of leg	1.1	0.6	1.6
R99	Other diseases respiratory system	1.1	1.4	0.8
D85	Duodenal ulcer	1.1	1.7	0.5
H71	Acute otitis media/myringitis	1.1	1.2	1.0

n = total number of patients.

The database can provide a monitoring function for particular health problems. Furthermore, the data can be used for practice audit, medical education and health management. The feasibility of using the database for practice audit has recently been studied.<sup>14</sup> All patients on the database with non-insulin dependent diabetes mellitus were identified. Each practice received a floppy disc listing the patients in their practice that had been identified. The practice health information system was used to print a datasheet with details about blood glucose levels which had to be filled in and returned for each patient. This proved to be a simple method of gathering data. Data from the registration network have also been used in the analysis of the problem-based medical curriculum at our medical faculty.<sup>15</sup>

A steering committee of the network ensures that the research projects are scientifically relevant to the field of general practice and that the information needs of the project can be fulfilled by data from the database. Furthermore, the committee assesses

the workload for the general practitioners involved and the possible inconvenience to patients before deciding upon collaboration with a particular research project.

### Discussion

The registration network of family practices differs from other sentinel networks in several respects. It is not a register of morbidity in general practice, since it does not include minor intercurrent diseases such as influenza, gastroenteritis, pruritus or urinary tract infections. The network focuses on chronic health problems, including risk factors such as smoking. The general practitioners involved do not gather data for three or four network studies but instead continuously update the patient characteristics and problem lists of all their registered patients. Hence, the database at the Medical and Social Information Center is an up to date index from which selections based on personal and health characteristics can easily be made.

A computerized health information system which supports the general practitioners during the process of problem definition and coding is absolutely necessary. However, it is the general practitioners who have to adapt to a strict discipline of making and then updating the problem lists of their patients. They have to do this not only when they have seen a patient but also when they receive a letter from a specialist. To enable practitioners to incorporate this process into their normal work, the definition of what constitutes a problem has to fit in with their daily work; it also has to suit the purpose of the registration network. The working definition of Sandlow and Bashook<sup>10,11</sup> is neither too open nor too strict. It provides general practitioners with some freedom in determining whether or not to put something on the problem list. This freedom, although limited, results in some inter-doctor variance, which will be low for clearly defined diseases such as cancer or diabetes mellitus, which meet quite specific *ICHPPC* criteria. When dealing with other health problems such as low back problems or psychosocial distress, this inter-doctor variance is likely to be higher since the criteria leave the general practitioner more room for interpretation. Minimizing this inter- and even intra-doctor variance is one of the goals of the quality control programme. However, there is another factor which influences variation. In writing a problem list, general practitioners have to rely on their own records, and sometimes on letters and notes from their predecessor. This information is not always available, complete, understandable or accurate. Formulation of problems in retrospect is therefore, sometimes difficult in view of the rules of problem definition. In most of these cases, verifying the *ICHPPC* criteria is impossible. Clear diagnoses from the past are therefore accepted without further verification. In future the correct use of *ICHPPC* criteria will be investigated, when these become available for a particular disease.

The chief goal of the registration network of family practices — to establish a computerized anonymous database with certain patient characteristics and all relevant health problems — has not yet been fully accomplished. Selection bias does not appear to be a problem, but this cannot be excluded until all patients have been added to the database. Users of the database have to be aware of these problems when using it as a sampling frame or as a starting point for further research. Nevertheless, several researchers are already making use of the database for their projects.

Although most general practitioners are still entering new patients onto the database, many of them have already discovered the possibilities of the health information system for daily patient care and practice audit. All kinds of selections can be easily made, such as selecting patients who have an indication for vaccination against influenza, or patients with hypertension, diabetes mellitus or any other health problem, which is stated on the problem list. The registration network of family practices stimulates not only research in general practice but also enables general practitioners to engage in practice audit.

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# RCGP

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## RESEARCH FUNDING

Applications are now being received for grants for research in or relating to general medical practice, for consideration at the May 1992 meeting of the Scientific Foundation Board. In addition to its general fund the Board also administers specific funds including

the Windebank Fund for research into diabetes.

The Scientific Foundation Board's definition of research is catholic and includes educational research, observational as well as experimental studies, and accepts the methodologies of social science as valid. It is not in a position to fund educational activities.

If the study involves any intervention or raises issues of confidentiality it is wise to obtain advance approval from an appropriate research ethics committee otherwise a decision to award a grant may be conditional upon such approval.

Studies which do not, in the opinion of the Board, offer a reasonable chance of answering the question posed will be rejected. It may sometimes be useful to seek expert advice on protocol design before submitting an application.

Care should be taken to ensure that costs are accurately forecast and that matters such as inflation and salary increases are included.

The annual sum of money available is not large by absolute standards and grant applications for sums in excess of £15 000 are unlikely to be considered.

Application forms are obtainable from the Clerk to the Board at: The Scientific Foundation Board, 14 Princes Gate, London SW7 1PU. *The closing date for receipt of completed applications is 20 March 1992; any forms received after that date will, unfortunately, be ineligible for consideration.*