

NEW STUDY

The Utrecht Health Project: Optimization of routine healthcare data for research

Diederick E. Grobbee¹, Arno W. Hoes¹, Theo J.M. Verheij¹, Augustinus J.P. Schrijvers¹, Erik J.C. van Ameijden² & Mattijs E. Numans¹

¹Julius Centre for Health Sciences and Primary Care, University Medical Centre Utrecht, Utrecht, The Netherlands; ²Municipal Health Service Utrecht, Utrecht, The Netherlands

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Abstract. *Background:* Research on the impact of changes in healthcare policy, developments in community and public health and determinants of health and disease during lifetime may effectively make use of routine healthcare data. These data, however, need to meet minimal criteria for quality and completeness. Research opportunities are further improved when routine data are supplemented with a standardized ‘baseline’ assessment of the full population. This formed the basis for a new study initiated in a newly developed large residential area in Leidsche Rijn, part of the city of Utrecht, the Netherlands. *Methods:* All new inhabitants are invited by their general practitioner to participate in the Utrecht Health Project (UHP). Informed consent is obtained and an individual health profile (IHP) is made by

dedicated research nurses. The IHP is the starting point for the UHP research database as well as for the primary care electronic medical records. Follow-up data are collected through continuous linkage with the computerized medical files recorded by the general practitioners. UHP staff in each practice takes care of quality management of registration as well as data handling. *Results:* Currently, over 60% of invited new residents in the area have given informed consent with participation steadily increasing. *Discussion:* The Utrecht Health Project combines key elements of traditional epidemiologic cohort studies with the current power of routine electronic medical record keeping in primary care. The research approach optimizes routine health care data for use in scientific research.

Key words: Continuous registration, Follow-up study, Health monitoring, Primary care, Study population

Introduction

Leidsche Rijn is a newly developed residential area west of the city of Utrecht, the Netherlands. To date (spring 2004) some 15,000 new inhabitants have settled, and by 2023 over 80,000 new inhabitants are expected to have found their homes in this area (Figure 1). The unusual situation of a newly built city inhabited in a relatively short period of time, with the concomitant need to establish a new health care infrastructure offered the opportunity to establish a new study for health care monitoring and epidemiologic research, the Utrecht Health Project (UHP). UHP aims to answer questions about the occurrence of disease and its determinants, as well as question on the effects and costs of health care interventions and organizational changes. Because data are linked from various health care providers, individuals can be tracked in health and disease. Data from youth health care, primary and secondary care, nursing homes and rehabilitation centres are included. Consequently, the disease careers of individuals and groups can be assessed and compared in different periods and under varying health care strategies.

Research approach

The research approach is twofold. First, information regarding the participants’ health status and disease history is recorded during a dedicated interview and examination: the Individual Health Profile (IHP). Those IHP data relevant to individual healthcare are added to the GP’s electronic medical record. From a research perspective, the data are essential to gain insight into the phase preceding an indicated health care contact and to learn about individual and population determinants of future disease. In the IHP specific aspects are covered for different age groups (<18 years, 18–65 years, elderly) using interview assisted questionnaires and biometrical measurements taken. In addition a blood sample is obtained that is frozen and stored for future analyses (Table 1). The questionnaires data include questions on psychiatric conditions in adults SCL-90 [2] and in children SDQ [3], on functional abdominal complaints [4], cardiovascular disease [5], and general health and well-being [6, 7]. Follow-up data are continuously collected from routine health care data. The Dutch healthcare system provides for a fixed list of inhabitants to be taken care of by each

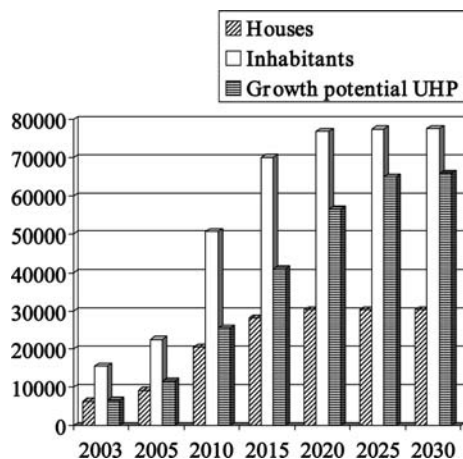


Figure 1. Prognosis of houses and population growth in Leidsche Rijn 2003–2030, Actual and potential of participation in UHP.

Table 1. The Individual Health Profile (IHP)

Medical history

Chronic disorders
Operations
Infectious diseases, allergies
Medication
Risk factors

Questionnaires

Social and economic status (education, occupation)
Health (diseases, medication)
Physical problems
Life-style factors (alcohol, smoking)
Use of health care (GP, specialists, hospitals, physiotherapists, dentists)
Accidents
Rand SF36 questionnaire (well-being) [7]
SCL90 (psychiatric diagnosis list) [2]
SDQ (psychosocial condition of children) [3]
GHQ12 (general health status) [6]
Rose (cardiovascular disease) [5]
VvZ Dyspepsia (abdominal complaints) [4]

Biometry, risk factors and biochemistry

Age, gender
Height
Weight
Blood pressure
Serum cholesterol, LDL cholesterol
Serum glucose

Storage of spare blood samples

GP in each healthcare centre with access to secondary care only via the GP, which assures a complete coverage of subsequent medical events. The computerized medical records in general practice include diagnostic data (blood pressure, physical examination findings), additional investigations (e.g. laboratory results, radiology, endoscopy), summarized patient history, treatment (prescribed drugs as well as surgery and other interventions), and refer-

als. As part of the UHP, all GPs and assistants are trained and supported in computerized recording and coding [8].

Privacy protection

The approach to data collection depends heavily on state-of-the art information technology. Without creating an unwanted possibility to trace back data to specific individuals, files can be gathered and links can be made from the GPs medical record to other files, including those from pharmacies, hospitals, cancer registries, mortality registries, hospital data and the Municipal Health Service. Protection participant's privacy has been a leading principle of the UHP. The design of the study has been discussed with representatives of the Dutch Patient and Healthcare Consumer Platform and has been approved by the Dutch Health Care Inspectorate. The masking of all personal data for researchers and for other possible users of LRGP has been regulated in a legal document. The study has been approved by the Medical Ethics Committee of the University Medical Centre Utrecht. All participants give written informed consent. Dedicated research nurses are assigned to each general practice to conduct the IHP and are bound to the professional privacy regulations of the healthcare centres. An unique code is given to each new participant and all data are sent to the central database under that code number. The same procedures are used for follow-up data to assure that data retraceable to participants are not accessible, either intentionally or by accident, by unauthorized individuals. Participants note in their informed consent whether they want to be informed on risk factors for disease that may be detected in their LRGP file during a later stage of the study. If disclosure of such information is declined, it will not be given. In case a participant decides to withdraw from the study after the IHP, the data will be unlinked from the code number without disrupting the medical file in the GPs office.

State of affairs

Currently over 12,000 inhabitants have been approached via the healthcare centres in the area. Preliminary analyses estimate the overall response rate at 65%. This percentage is expected to further increase with a growing number of participants. After starting with mostly childless, double-income, two-car couples in their thirties, the residents in the area are now beginning to become more representative of the average Dutch population. The population characteristics in this early stage enabled us to successfully embed a sub-study on respiratory diseases in new-born children in the Utrecht Health

Project. This “Whistler” study recently welcomed her 600th baby-participant [9]. The completion of the houses in Leidsche Rijn is currently behind schedule and many of the facilities necessary for a comfortable residential area are still under construction, but developments improved during 2004. About 20–40 individuals still complete the IHP procedure weekly. The planned growth of the number of participants in LRGP is between 1500 and 3000 per year, paralleling the growth of the population itself and of the general practices in the area (Figure 1).

Relevance

Innovations are continuously introduced in health care. Typically, systematic scientific evaluations of effects and costs are not performed. Intriguingly, large amounts of data are gathered as part of routine patient care but very little of these are used for research. Such data offer a major resource to establish the quality and functioning of the health care system, the effects of health care policy, and factors that influence the occurrence and course of disease. The fact that routine data are rarely used for research partly reflects quality limitations. Routine data are obtained for a medical reason and generally lack important basic patient characteristics, such as medical history, socio-economic characteristics, and risk factors. Consequently, the ‘disease career’ of individuals remains hidden and differences arise in the degree to which certain groups can be followed. In UHP routine healthcare data are optimized and completed for scientific research so that all individuals can be followed anonymously over time and through the health care system. Apart from the research relevance, the residents of Leidsche Rijn will profit from the personal health evaluation and advice that is part of the IHP. Secondly, in the area, a primary health care structure is built up that can be tested, guarded, and if necessary, amended on the basis of the data. Insights into the results of the local health care policy as well as other experiences and findings of the project will be valuable for the city and the region. The eventual aim, however, is to create a solid and continuous research infrastructure to generate general medical and health care insights as a basis for evidence-based medicine and health policy.

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Address for correspondence: Dr M.E. Numans, Julius Centre for Health Sciences and Primary Care, UMC Utrecht, P.O. Box 85060, 3508 AB Utrecht, The Netherlands
E-mail: m.e.numans@umcutrecht.nl